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Literature review and mapping of supportive services for children and young people with cancer

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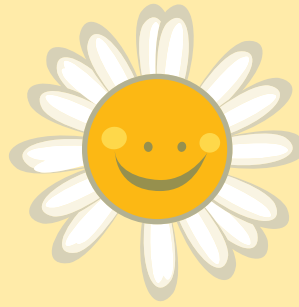
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**cancer fund
for children**

Literature Review and mapping of supportive services for children and young adults experiencing cancer

Report on Phase II of a collaborative endeavour:
Literature review and mapping exercise
January –July 2018

This report has been compiled by the following team.

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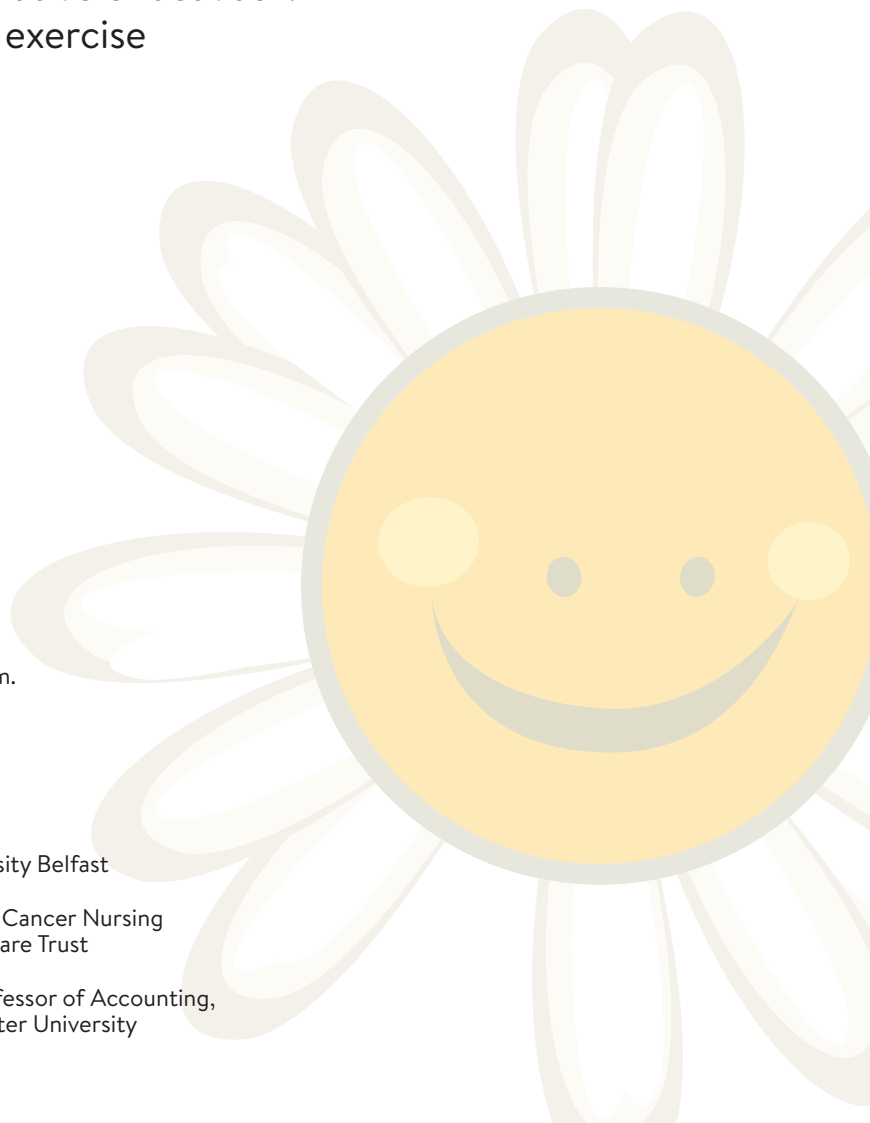


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Foreword from Director of Services

The sad reality is that every week in Northern Ireland another three children and young people aged 0-24 years old will be diagnosed with cancer.

As Northern Ireland's leading children's cancer charity, Cancer Fund for Children understands the devastating impact a cancer diagnosis and its treatment has on the whole family, and that beyond the essential medical care, there is a family life that needs to be rebuilt.

From the point of diagnosis our team of Cancer Fund for Children Cancer Support Specialists are here to help, guide and support families on the hospital ward, at home, in their community, and at our therapeutic short break and residential centers in Newcastle, Co. Down.

Our support is focused not just on the diagnosed child or young person, but on the whole family. Our aim is to empower, connect and strengthen, so each family is equipped to deal with whatever the future may hold.

Cancer Fund for Children is extremely proud of the services they have developed over the last decade in which they have been widely recognised as an integral part of the psychosocial support offered to families that compliment and support the essential clinical care that cancer patients receive within the National Health Service in Northern Ireland.

Cancer Fund for Children has been working in partnership with Queens University Belfast, School of Nursing and Midwifery since December 2014. During that time our collaborative relationship has developed to further the aims of Cancer Fund for Children. The collaboration draws together Cancer Fund for Children services teams' knowledge and skill and academic research expertise, with the lived experience of families impacted by cancer. It is allowing us to better understand and produce evidence of the impact of our therapeutic services on families.

This report represents the second phase of the project. It contains results of a review of international evidence about the benefits of supporting children, adolescents and young adults diagnosed with cancer and maps that evidence to the current service provision portfolio of Cancer Fund for Children.

At Cancer Fund for Children we believe the services we offer are innovative and unique and collectively contribute to the improved wellbeing of diagnosed children and their immediate family. This report reassures us that the services Cancer Fund for Children provide are developing in line with international efforts, as blueprints for effective evidence-based psychosocial interventions in the area of childhood, adolescent and young adult cancer services.

This very welcome exercise clearly articulates the need for further research into this relatively new subject area whilst outlining several key action points that characterise our work as a world class, family focused cancer support service.

It is reassuring to see the growing evidence base produced by professionals internationally, who are working tirelessly developing a range of interventions that seek to improve the outcomes for this group of vulnerable children and young people and their families. This report provides valuable information that is essential in helping Cancer Fund for Children assess its current services provision portfolio, track our progress against existing evidence and identify service development opportunities.



A group of young people who have a parent with cancer displaying artwork created during residential group work.

The natural next step for Cancer Fund for Children is to continue to foster an effective research culture within the organisation and to undertake further rigorous evaluations and embrace advanced research methods that can showcase the pioneering work that is already underway.

We will continue to cultivate our model of collaboration involving families, service teams and academics working together to drive service developments. That way we can meet the needs of local families and draw from as well as contribute to the international evidence on best practice.

As Director of Services I'd like to take this opportunity to thank the service teams for their dedication and professionalism and to thank our young people and families for completing evaluations with such generous and encouraging feedback. I would also like to warmly thank Dr Karen Galway and Dr Conall O'Rourke from Queens University Belfast, School of Nursing and Midwifery's research team for their support, expertise and guidance as well as Dr Cherith Semple for her time and generous contribution as External Advisor to the project.

Phil Alexander

Chief Executive Officer (Interim)
Cancer Fund for Children

Executive Summary

Introduction

- This report represents Phase II in a collaboration between Cancer Fund for Children and the School of Nursing and Midwifery at Queen's University Belfast. The Phase I report was written after holding a workshop with staff, clients and researchers to explore the perceptions of services provided by Cancer Fund for Children (CFC) and to assess future pathways to developing an evidence base for the impact of services delivered within the organisation.
- Phase I report included a 'Roadmap' which indicated areas of development for CFC and suggested undertaking a thorough review of the literature to map the services provided by CFC against the existing evidence for psychosocial support in Children and Young Adults (CAYAs) diagnosed with cancer.

The aim of this report was two-fold. Firstly, to review the evidence for supportive or psychosocial work with CAYAs, and their families by asking what works, for whom and in what format? The second aim was to map the evidence of what works, to the features and characteristics of the supportive work underway at CFC.

- We will report on a thorough review of the evidence first and then map the evidence to the services within CFC. This provides a snapshot of the evidence base in context of work underway at CFC, showcasing the excellence already in place and providing a basis for future development of services and evidence of what works best for families.

Review of the evidence

Method

- Many authors had reviewed the literature recently, reflecting a strong and growing interest in this area of study. In order to cover as much material as possible within a short time frame, a review of reviews was carried out for this report. A review of reviews focuses on summaries of evidence that have already combined the results from a variety of settings.
- This review of reviews focused on support for CAYAs with a cancer diagnosis provided in hospital, community or residential settings. In line with CFC service model we only included informal psychosocial support,

therefore research focused on formal psychotherapy was excluded from the review.

- We included reviews of psychosocial and supportive interventions for CAYAs with a cancer diagnosis that were designed to address wellbeing, self-esteem and autonomy. We excluded reviews that were exclusively focused on siblings or parents alone. We also excluded formal psychotherapies and therapeutic interventions designed to address pain, fatigue, treatment engagement or survival. These were considered outside the remit of this work.
- Out of a potential list of 1427 abstract summaries of publications, 84 full text papers were examined for relevance. Of these, 11 reviews met the criteria set out above.
- We applied an academic quality appraisal process to critically appraise the reviews. Only 1 of 11 met the criteria for "moderate" quality based on the process, with remaining reviews either "low" or "critically low". However, the academic standards are not specifically designed for application to this topic and are incredibly high standards.
- Nevertheless, the quality appraisal process emphasises that there is a great deal more work to be done in order to be fully confident in the evidence about what works, for whom and in what context. Despite this concern, the existing evidence does provide a good initial indication of what is currently thought to work.

Results of Review

- The 11 reviews were published between 2008 – 2017. They included data from 128 peer reviewed published research studies of psychosocial interventions with CAYAs with cancer, involving well over 1200 individuals (CAYAs or parents) affected by cancer.
- Within these reviews, four types of interventions were described; therapeutic recreation camps, education or information provisions, peer or emotional support and skills training.
- Most of the evidence that exists comes from testing the effects of therapeutic recreation camps.
- Therapeutic camps appear to provide short-term benefits including; promoting independence, encouraging positive coping, developing emotional skills, and improving self-confidence.

- Furthermore, including the whole family in therapeutic camps leads to positive coping for the family.
- The quality of the research evidence means it is difficult to say which elements within the therapeutic camps (i.e. physical activities, crafts, discussion workshops, leisure time, group-based elements, individual elements, family involvement etc.) have the most impact and it is also difficult to say anything about longer-term outcomes.
- The second most commonly assessed interventions were those providing education and information.
- Topics addressed include sexual development and fertility, self-care behaviours, cancer and treatment knowledge and coping strategies. A variety of approaches were used including face to face meetings as well as written information such as workbooks, to aid the process.
- While evidence suggests that individuals valued the opportunity to share emotions and experiences, more evidence is needed to provide evidence of benefits beyond knowledge alone.
- It is worth noting the potential for information e.g. details about types of cancers, side effects, impact on family and coping techniques, to lead to distress as well as empowerment and it is worth considering whether formal or informal education settings are preferred by the target group.
- Peer/emotional support was a third support theme that emerged from the review of evidence, again approached in a variety of ways including online forums and advocacy workshops.
- Although participants highly praised some of the initiatives, the evidence base for educational and information focused support is certainly underdeveloped and would benefit from additional research.
- While the evidence is limited, the added value of peer-designed support was widely recognised in the literature we reviewed.
- Skills training was the final theme identified amongst the evidence reviewed but similar to peer-support, specific skills training approaches were not always well evaluated or tested for evidence of effectiveness.
- Both peer-support and specific skills training approaches to support were often integrated as part of therapeutic camps and other broader interventions. It is therefore difficult to be confident in the impact of these elements, without them being evaluated in isolation.

Discussion of Review Findings

- Important and successful characteristics of supportive (psychosocial) interventions are highlighted as below and in **Box 1**;
 - a. Therapeutic contact over a longer period of time was a powerful factor in programme success: six or more sessions spanning more than three months appeared more successful than shorter interventions.
 - b. Effectiveness of skills training, in particular, communication skills may be most effective when delivered by psychology or counselling-trained professionals.
 - c. Teaching positive coping strategies as well as improving parent-child communication may leave families better equipped.
 - d. Development of coping skills early after diagnosis was a key characteristic of successful transition from acute care to survivorship.
 - e. Informal interactions between participants facilitated an exchange of knowledge and experience around cancer.
 - f. Consideration should be given to whether participants want formal education sessions.
 - g. Difficult to discern the contribution of nonspecific (e.g. peer-support) versus specific (e.g. skills training).

Box 1. Features of successful CAYAs supportive interventions

1

Those reviews that commented on the specific characteristics of therapeutic support mentioned five characteristics;

1. A parent or family component
2. Longer therapeutic contact
3. A focus on communication and coping skills
4. Recognition of the value of informal knowledge and skill sharing, through peer-interaction
5. Participant input into the design of the service or intervention.

- Overall, the literature certainly provides evidence of a growing interest in supporting the use of informal therapeutic approaches with CAYAs with cancer and other life limiting conditions.



A group of young people taking part in a team building activity.

- We identified gaps to be addressed in future research;
 - a. Consider support needs by age and stage of treatment
 - b. Co-produce peer designed and peer delivered programmes
 - c. Needs assessments should be mapped to components of the intervention or service
 - d. Use of a theory of change or logic models would help to show how the intervention is expected to work i.e. which components address which needs
 - e. Components of the therapeutic support should be well designed and articulated to allow for replication studies
 - f. Mixed-methods evaluations are needed, including interviews to capture in-depth details of experiences of CAYAs and their families
 - g. Careful planning of how to best measure impact would strengthen the evidence of effectiveness (validated outcome measures of effectiveness need to be appropriately selected and used)
 - h. Rigorous larger scale studies that consider longer term impact are required

Conclusion of Review

- Key conclusions of the review of the literature are outlined as follows:
 - a. Psychosocial interventions for CAYA's with cancer fell into four broad themes; therapeutic recreation, educational, skill training, and peer support.
 - b. Interventions sought to address a number of key areas of need for CAYA's;

- Education
 - Skills
 - Peer-support
 - Family Engagement
 - Agency
 - Normalcy
- c. Therapeutic respite camps were the most commonly reported and most positively reviewed interventions.
 - d. Many interventions combine aspects of the above themes making it difficult to conclude what specific characteristics produce positive outcomes.
 - e. Characteristics that do appear to improve outcomes are;
 - Greater amounts of therapeutic contact
 - Family involvement
 - A focus on coping and communication skills
 - Informal knowledge sharing
 - Participant driven intervention design
 - f. While there is growing interest and investigation into therapeutic respite camps, research in the area is underdeveloped and gaps exist in the academic literature.

Mapping Process

- The first aim of this collaborative report (Phase II) was to review the evidence for supportive or psychosocial work with children, adolescents and young adults (CAYAs), and their families by asking what works, for whom and in what format?
- The second aim was to map the evidence of what works, to the features and characteristics of the supportive work underway at CFC.
- The mapping was carried out with the assistance of the CFC steering group members, who liaised with a wider group of CFC Cancer Support Specialists and researchers from Queen's University Belfast.
- Results from the review were circulated, which identified six key categories of 'needs identified'; education, skills, peer support, family engagement, agency and normalcy.
- Data extraction forms that had been designed for use in the review process were modified for the mapping process and used by CFC's Cancer Support Specialists

to summarise aspects of the service they deliver, under the various categories of 'needs identified'.

- The mapping process considered six distinct services provided by CFC;
 1. Family Short Breaks at Daisy Lodge
 2. Family Group Work at Daisy Lodge
 3. Young Adult Group Work at Daisy Lodge
 4. Residential Work at Narnia
 5. 1:1 Ward Support for a Diagnosed Child
 6. 1:1 Community Support for a Diagnosed Child
- The steering group considered and discussed the six summary documents produced, against the main evidence gathered in the review of the literature.
- The researchers then consolidated the discussions and mapped the service components to the evidence from the literature.
- It is worth reiterating that the literature often did not clearly articulate the components within the therapeutic support evaluated and tested, therefore we often do not know whether the service components in CFC are equivalent to those reported in the literature. However, the mapping was carried out based on the details available.

Results of the Mapping Process

- The mapping process (page 34) highlighted a high degree of evidence based support for the services provided by CFC.
- In particular, Family Group Work and Residential Work at Narnia employ a number of evidence based components in addressing the needs of CAYAs with cancer.



Cancer Fund for Children's therapeutic short break centre, Daisy Lodge.

- The three most prominent evidence based characteristics of the work at CFC were; family involvement, peer-support and agency/individuality. These characteristics were put forward by CFC's Cancer Support Specialists as key aspects of the programmes that are delivered to clients and were outlined in the six summary documents.
- The results also indicate that CFC offer a number of additional unique features that do not appear anywhere in the literature and warrant evaluation and testing to showcase impact.
- In addition, a number of notable components, or Unique selling points of CFC services did not appear in the academic literature despite clear benefits for service users, such as the quality of the architecture and accommodation standards, the catering and amenities provided, and the outstanding beauty of the location in the Mourne Mountains, in Northern Ireland. These aspects of CFC service provision warrant robust evaluation.
- The advocacy function provided by ward and community based specialists providing 1:1 services also appeared to be a highly novel and unique selling point of CFC service provision that warrants robust evaluation.
- Although the services of CFC appear to address many of the needs highlighted in the literature, comprehensive evidence based evaluation of these services is not possible based upon the mapping process alone.

Key Findings and Future Directions

- The work carried out to produce this Phase II Literature Review and Mapping Report provides further support to the evidence presented in the Phase I report of the very tangible and highly valued impact CFC is having on CAYAs with cancer and their families (Galway and Grant, 2016).
- The literature review and mapping process indicates that CFC are addressing identified needs, using approaches that are well supported in the international literature.
- The report also indicates that CFC offer a number of additional unique features that do not appear anywhere in the international literature and warrant evaluation and testing to showcase impact.
- Key findings are summarised below;
 - a. Services provided by CFC, particularly those within Daisy Lodge and Narnia, are addressing key areas of need routinely identified in the academic literature,

such as education, skills, peer-support, family engagement and a sense of agency and normalcy.

- b. The inclusion of family members in respite care services aligns closely with the academic evidence base and the continued focus on communication and coping skills as a means of improving family functioning is recommended.
- c. In line with the literature base, services should continue to utilise peer-support approaches when working with CAYA's, placing emphasis on fostering opportunities for informal knowledge and skill sharing.
- d. The current practice of affording service users a high degree of autonomy and control over their respite care is also supported by the current academic evidence, and may improve both engagement with services and positive outcomes for service users.
- e. Characteristic of the Daisy Lodge and Narnia services, such as the restorative environment, have not yet been investigated in the academic literature and should be further evaluated.
- f. No interventions in the academic literature matched the 1:1 Ward Support or 1:1 Community Support services.
- g. Both services appear highly novel and may potentially serve as blueprints for future interventions internationally.

d. Economic evaluation of current services is needed alongside consideration of the resource costs involved in individual service components.

- e. Combined quantitative (questionnaire/psychometric tools) and qualitative (interview/open ended survey) methods are needed for service evaluation across all services.
- f. There is need for a large scale controlled study examining the impact of CFC services on CAYA's with cancer and their families.

Recommendations for future research based on the gaps identified, are presented on page 7 above and elaborated in the full report on Page 45.

Recommendations for service development

- a. There is need for clear, common language to describe and define the scope of individual services. Complex, multicomponent services such as 1:1 Community Support requires further refining and standardisation.
- b. Each service should have a commonly agreed service "pamphlet", including;
 - a. Description and length of the service
 - b. Areas of need addressed
 - c. Therapeutic characteristics of the service
 - d. Outcome goals of the service
- c. Working groups composed of staff and service users should contribute to the standardisation of service descriptions and the identification of target outcomes of treatment (e.g. self-confidence, family communication, knowledge around illness).

1. Introduction and rationale for the review

This report represents the second project in an on-going collaboration between Cancer Fund for Children (CFC) and the School of Nursing and Midwifery at Queens University Belfast (QUB). Phase I of the collaboration resulted in a Research Roadmap report. The first two priorities set out in the Phase I Research Roadmap report as referenced in **Box 2** below are addressed.

Box 2. Extract from Research Roadmap Report: priorities for Cancer Fund for Children (Galway and Grant, 2016)

2

1. Mapping the current service provision portfolio of Cancer Fund for Children is considered an essential first step in providing improved clarity of the aims and outcomes of the charity as a whole. It was felt that without these parameters to work with, measuring success would become increasingly difficult and complex. In the interim, some mapping work has been completed, which will be of great benefit to moving the collaborative process forward.
2. In order to identify gaps in the existing research literature and subsequently highlight the unique selling points of the services provided by the charity, reviewing the literature was felt to be an important step in the process towards strengthening the position of the charity, within the cancer services landscape.

This Phase II report presents a literature review and mapping exercise.

Within this second report, we have included

- a review of internationally published peer-reviewed literature describing the state of the evidence-base in supporting children, adolescents, and young adults (CAYAs) experiencing cancer and their families.
- The evidence has also been mapped to a selection of the services provided by CFC.
- The review and mapping have been carried out in order to;
 1. identify what is already known to work,
 2. make suggestions around providing best practice,

3. identify the gaps in the literature and
4. highlight the innovations in service delivery at the Northern Ireland Cancer Fund for Children.

The report concludes by outlining recommendations and distinct opportunities for future development of evidence-based services.

Why carry out this work?

Cancer can disrupt development in children and their siblings and that can impact on relationships in the family unit (Alderfer et al. 2010, Krattenmacher et al. 2012, Long et al. 2011). Although only a small minority of families experience clinically defined disorders, a higher proportion experience delays in normal psychological and social development. To date, we know very little about the educational impacts, changes in quality of life, coping strategies or illness related factors that result from being part of a family dealing with a cancer diagnosis.

The published literature indicates that ‘family-focused’ cancer support provision such as that provided by Cancer Fund For Children, could be effective at reducing the risk of social, behavioural and relationship difficulties, within families (Alderfer et al. 2010) because positive family functioning is known to be associated with lower child distress (Long et al. 2011). However, despite early studies indicating the importance of wider support networks for those experiencing cancer, particularly children (Long et al. 2011), to date family approaches to reducing risk such as the family-oriented services provided by Cancer Fund for Children, are largely lacking a robust evidence-base.

Therefore, this review has been carried out to identify which types of services have been robustly evaluated, and how those services compare to the work of Cancer Fund for Children.



Cancer Fund for Children's therapeutic short break centre, Daisy Lodge.

Aims:

1. To identify, evaluate, and summarise the available literature on psychosocial interventions for CAYAs with cancer.
2. To map the services provided by Cancer Fund for Children to the existing evidence base in terms of;
 - Design and content
 - Needs of service user addressed
 - Evidence based characteristics
3. To provide Cancer Fund for Children with a globally recognised common language for defining their services.
4. To identify other international service providers, working on innovations to provide support for CAYAs experiencing cancer.

Objectives:

1. To review the evidence on supportive interventions for CAYAs experiencing cancer.
2. To identify and classify the prominent intervention approaches used with CAYAs.
3. To identify evidence based intervention characteristics which may be incorporated into CFC services.
4. To point to future research that could be carried out as part of the collaboration where research evidence is weak, or inconclusive.

The Integrated Services Model and the Service Framework Handbook currently in use within Cancer Fund for Children has been used to inform the mapping process.

2. Methodology

2.1 Scope of review: service focus and approach

The purpose of this review is to summarise and quality assess the available evidence surrounding psychosocial interventions for CAYAs with cancer. Initial scoping of the published literature revealed a breadth of literature published in the area including a number of systematic reviews of relevance. Given the significant scope of the current investigation it was decided a review of reviews would be appropriate. A review article is a type of study that succinctly summarises the current available knowledge on a topic. It identifies and collects individual research studies and draws conclusions by comparing between their results. In this way, a review study can be useful in giving an overview of all the research available on a given topic. A review of reviews goes one step further by collecting and comparing between review studies in a given area. This approach can be extremely valuable in identifying the most conclusive and comprehensive evidence on a topic.

The current report is interested in review articles that collect and compare primary research interventions relating to CAYAs with cancer. This means that each review article may include a number of interventions of interest. As the current report is a review of reviews, the authors examined the findings the findings and conclusions of a number of reviews to identify themes relevant to the research aim.

Through an iterative process involving discussion about Cancer Fund for Children's Integrated Services Model and reference to the published literature, parameters for the review and mapping exercise were agreed upon. This refinement process resulted in a focus on distinct aspects of current service provision. The focus was agreed as services focused on CAYAs diagnosed with cancer, including community based therapeutic support and residential therapeutic short breaks and the core components within these services.

2.2 Searching the literature

Five databases¹ were systematically searched in February 2018 for evidence relating to psychosocial and supportive interventions aimed at CAYAs with cancer. In the context of the current review, psychosocial support is defined as;

Box 3. What we included in this review of evidence

3

Included

- Reviews of psychosocial and supportive interventions for CAYAs with a cancer diagnosis
- Reviews of interventions designed to improve wellbeing self-esteem and autonomy

Excluded

- Reviews of interventions focused on parents or siblings alone
- Reviews of interventions focused on formal psychological therapies designed to address pain, fatigue, treatment engagement or survival

- Interventions or programmes aiming to address the way a person thinks or feels about themselves and others as well as their ability to adapt and cope with daily life.

While the current report does not include interventions that are exclusively designed for parents or siblings of a CAYAs, interventions aimed at CAYAs which include a parent or sibling component were included. Several keywords², developed through examination of relevant literature were used in the search. The search was not limited by time but only English language reviews were included due to resource constraints. Articles from each database were then gathered together and duplicates were removed. Title and abstract screening was conducted by the first author (COR) with 25% also examined by the second author (KG) to improve rigour, by ensuring both authors agree on the criteria. The remaining articles were then checked for relevance and a decision was made to include or exclude. In cases of disagreement, the third author (CS) was available to double check and help make a decision. Reference lists of the final included studies were also hand searched in case any more relevant studies were referenced.

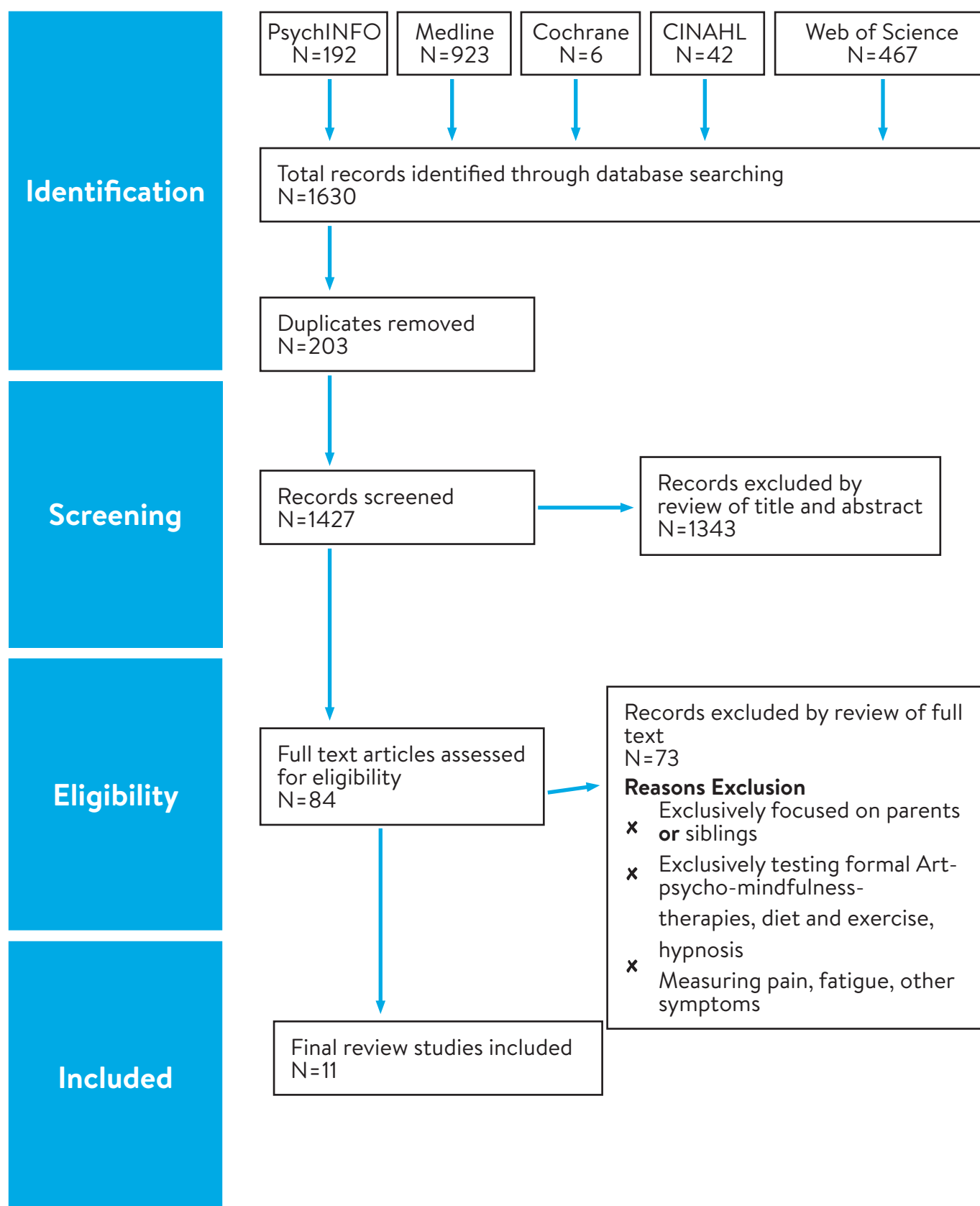
2.3 Inclusion and exclusion criteria

We included any systematic review articles that explicitly reported on supportive face-to-face individual or group-based interventions for CAYAs with a diagnosis of cancer. Inclusion criteria, summarised in **Box 3**, focused on the population, intervention, and outcomes of interest. The population of interest was CAYAs aged <24 years diagnosed with cancer. Reviews of adult populations (>18

1 Web of science, Medline, PsychInfo, CINAHL, Cochrane library

2 "child*", "young adult", "cancer", "Neoplasm\$", "psychosocial", "Psycho-educational", "wellbeing", "coping", and "resilience"

Figure 1. Flow Diagram showing the process of identifying published literature



years), or those without explicit age restrictions were only included if there was a clear indication that the population of interest was examined.

Supportive interventions were defined as non-pharmacological (drug or medicine), multi-factorial support that aimed to improve psychosocial wellbeing, restore self-esteem and identity, and foster a sense of control and autonomy. This excludes formal psychological and psychiatric interventions (e.g. cognitive behavioural therapy, family therapy, counselling, and psychotherapy), complementary or alternative therapies (e.g. massage therapy, hypnosis, and music therapy), as well as excluding exercise interventions.

Outcomes of interest were distress, coping, resilience, wellbeing, and quality of life. Studies assessing pain, fatigue, treatment engagement, or survival, were excluded.

As review studies are often broad in their scope, those which included interventions and outcomes outside the scope of these criteria were not excluded if there was a clear primary focus on the interventions and outcomes of interest. **Figure 1** shows a flow chart summary of included papers.

2.4 Data extraction and quality appraisal

Data extraction is the process of identifying and compiling (extracting) relevant information from publications for use in a review. In this sense, it produces summaries of each publication included, which can then be analysed and presented in the results section. This process was conducted by the first and second authors using a purpose built extraction table which included the following headings;

- Search dates
- Review aim
- Included study designs
- Inclusion criteria
- Exclusion criteria
- Participant numbers and characteristics
- Included interventions
- Outcomes measured
- Meta-analysis findings (if applicable)
- Primary findings
- Secondary findings
- Conclusions

- Recommendations
- Limitations.

Included publications were also assessed for their methodological strength through a process called quality appraisal. This gives the reader an indication of the trustworthiness of the research methods used. In a typical systematic review, quality appraisal is conducted on the individual intervention studies. However, in a review of reviews, quality appraisal is conducted on the review articles themselves. In line with other reviews of reviews (Smith et al., 2011; Duncan et al., 2017), the methodological quality of included reviews was assessed using the most recent available version of the Assessing Methodological Quality of Systematic Reviews 2 (AMSTAR 2, Shea et al., 2017). This tool includes between 13 and 16 questions (depending on the type of study examined) which are weighted as either critical or non-critical. This allows for four level categorisation of confidence in the review studies; high (none or one non-critical weakness), moderate (more than one non-critical weakness), low (one critical weakness with or without non-critical weakness), or critically low (more than one critical weakness). Studies were not excluded on the basis of quality appraisal scores. Data extraction items were compared between the first and second authors (COR and KG), with the third author (CS) available to arbitrate.

2.5 Study synthesis and presentation of results

Following data extraction and quality appraisal, included review publications were synthesised and interpreted. This process involved examining the data extraction details to identify patterns of findings between reviews, prominent themes and interventions of interest, and also to identify gaps in the research evidence. An inductive approach was used for developing themes, which means that authors did not impose preconceived intervention themes prior to conducting the narrative synthesis. A narrative synthesis was then produced by comparing the findings of individual reviews under each theme. Alongside this narrative synthesis, tables were produced which display summary information from each of the included reviews as well as prominent interventions in each theme. These are described below.

Table 1 displays the summaries of included review publications, organised by quality appraisal score with the highest scoring review appearing first. This table highlights the primary study designs and intervention types included in each review, as well as the results and recommendations from each review publication.



Cancer Fund for Children's Narnia residential log cabin.

Readers should note that, as mentioned above, the AMSTAR 2 recommends using four categories when reporting quality appraisal scores. For ease of comparison the current table has colour coded quality appraisal scores in line with these four proposed categories. Despite the AMSTAR 2 results indicating problems with the quality of the research, the evidence presented is the best available and represents significant progress in this relatively new field of study.

3. Results

The following section details the synthesised results of the eleven included reviews. An overview of the included reviews is provided alongside a summary of the quality assessment findings. This section then outlines the findings under four intervention themes;

- Therapeutic recreation camps
- Education/information provision
- Peer/emotional support
- Skills training

These were the most prominent intervention themes that emerged from the literature and findings and observations of the included reviews are discussed.

3.1 Overview of included studies

Eleven review papers were identified for inclusion in the current review (See **Table 1** Summary of included reviews highlighting intervention types and findings). Both the size and scope of reviews differed greatly, with the number of included studies ranging from four (Seitz, Besier, & Goldbeck, 2009) to 125 (Plante, Lobato, & Engel, 2001). Three studies focused specifically on therapeutic camp interventions (Martiniuk, Silva, Amylon, & Barr, 2014; Epstein, Stinson, & Stevens, 2005; Moola, Faulkner, White, & Kirsh, 2013), while four others focused more broadly on psychological (Sansom-Daly, Peate, Wakefield,

Table 1. Summary of included reviews highlighting intervention types and findings.

Lead author AMSTAR Quality appraisal	Study Designs	Intervention types	Primary findings	Recommendations
Ranmal et al., 2008 MODERATE	Randomised controlled trials (RCTs) (n=5) Non-random controlled trial (n=2) Before and after studies (n=3)	Group therapy (n=2) School reintegration (n=2) Computer based education & information provision (n=2) Planned play & story-telling (n=1) Art therapy (n=1) Self-care education (n=1) Digital CBT interactive package (n=1)	Social skills training led to significantly reduced state anxiety scores. Two group therapy interventions had no effect on psychological symptoms of participants. Self-care coping intervention had no significant effect on psychological outcomes.	<ul style="list-style-type: none"> More rigorous research needed around interventions to enhance communication involving children and adolescents with cancer. Interventions should be underpinned by the needs and preferences of target groups.
Walker et al., 2016 LOW	RCT (n= 6) Pre-post (n=4) Quasi-experimental (n=1)	Educational intervention (n=1) Skills training (n=3) Activity-based interventions (n=5) Physical activity, education, and coping (n=1) Peer support (n=2)	All but two interventions showed positive results on at least one outcome measure. However, little sustained improvement observed across interventions. Greater benefit appeared for individuals off-treatment vs on-treatment.	<ul style="list-style-type: none"> Further research is needed to examine the intervention characteristics most impactful. Further work needed to compare between outcomes for sub-groups of adolescents and young adults with cancer.
Bradford & Chan, 2017 LOW	RCT (n= 10) Controlled before and after studies (n=3) Before and after studies (n=4)	Exercise/healthy living programmes (n=9) Educational intervention (n=2) Peer support (n=1) Metacognitive therapy (n=1) Skills training (n=3) Cognitive behavioural therapy (n=1)	Lack of high-quality studies available. While 11 of the 17 included studies reported positive effects of their intervention on outcomes, these were all beset with methodological weaknesses. No conclusive evidence favouring specific interventions.	<ul style="list-style-type: none"> Strong need to undertake high quality RCT studies which include cost-effectiveness analyses. Interventions should consider employing face-to-face and peer-to-peer approaches which show potential in achieving positive outcomes.
Moola et al., 2014 LOW	Repeated measures (n=8) Pre-post test design (n=6) RCT (n=1) Cross-sectional (n=2) Historic cohort analysis (n=1) Qualitative (n=3)	Therapeutic respite camp (n=21) Interventions with cancer population (n=7)	Despite weak methodological quality, camp participation appears to offer some short term psychosocial benefits for children with chronic illnesses. Benefits included social outcomes, such as social interaction and acceptance.	<ul style="list-style-type: none"> Camp interventions need to be more theory driven and consistent in their reporting. Camp interventions should consider introducing a “camp philosophy” or mission/mandate for camp. Need for more rigorous and well evaluated camp interventions.
Epstein et al., 2005 CRITICALLY LOW	Pre-post design (n=9) Observational/qualitative (n=2) Pre-post repeated measures design (n=6)	Therapeutic respite camps (n=17) Interventions with cancer population (n=3)	During cancer camps children spent more time in physical activity (also at follow-up), engaged in significantly more social activities, displayed increased knowledge about cancer and its treatment, established relationships with other campers.	<ul style="list-style-type: none"> Need for greater theory driven research Need for more mixed-methods longitudinal research with adequate sample sizes and appropriate comparison groups. Greater focus should be placed on understanding and addressing children's needs and perspectives on camp.

Lead author AMSTAR Quality appraisal	Study Designs	Intervention types	Primary findings	Recommendations
Sansom-Daly et al., 2012 CRITICALLY LOW	Randomised trials (n=19) Non-random control trial (n=6)	Interventions with cancer population (n=7) Emotional/peer-support group (n=2) Educational/psychoeducational (n=3) Skill-based AYA alone (n=1) Skill based Parent/family (n=1)	Skill-based interventions delivered over multiple sessions may yield most positive results. Too few peer-support interventions for review.	<ul style="list-style-type: none"> Interventions studies must follow CONSORT guidelines for reporting. Future studies should ensure theory driven approach, adequate sample sizes, control groups where possible, and participant involvement in design. Focus on teaching "coping skills", particularly communication skills Six or more sessions over 3+ months may improve outcomes
Meyler et al., 2010 CRITICALLY LOW	Pre-post (n=2) Case-control (n=2) Multiple staggered baseline design (n=2) Pilot RCT (n=1) 2 group repeated measures (n=1) Cross-sectional (n=1) Longitudinal design (n=3) RCT (n=5) Randomised 3 group repeated measures (n=1) Prospective 2-group evaluation (n=1) Case Study (n=2)	Social skills training (n=2) Educational (n=2) Social/recreational (n=1) Therapeutic respite camps (n=3) Cognitive behavioural therapy (CBT) (n=3) CBT + Family Therapy (n=3) Family therapy (n=1) Behavioural intervention (n=6)	Few interventions met criteria for empirically validated treatments. However, evidence of beneficial outcomes was observed across majority of interventions including social recreation and camping programmes. Evidence suggests that family-based interventions which involve social-recreation activities and psychoeducational components have positive effects for families.	<ul style="list-style-type: none"> Effort should be made to provide universal level support for all family members affected by childhood cancer. Need for replication of existing interventions alongside more methodologically rigorous investigation into the pathways through which interventions affect change. Cost analysis is also required alongside examination of the cost-benefit of intervention components.
Seitz et al., 2009 CRITICALLY LOW	RCT (n=1) Non-random CT (n=1) Before and after (n=1) Random case-control longitudinal (n=1)	1:1 delivered counselling (n=1) Educational intervention (n=1) Group psychotherapy (n=1) Peer support (n=1)	Educational intervention and support groups had no significant impact. Distress increased for participants on treatment following group psychotherapy. Individual counselling session improved body image and reduced psychological stress.	<ul style="list-style-type: none"> Further interventions are needed which address issues such as school, job and school integration, social and communication skills, as well as coping with impairments and body image.
Martiniuk et al., 2014 CRITICALLY LOW	Case-series (pre-post tests) (n=14) Cross-sectional (n=4) Qualitative (n=1) Programme evaluation (n=1)	Therapeutic Respite Camp (n=20)	Camp positively impacts quality of life, emotional well-being, cancer knowledge, self-concept, empathy, friendship, and mood.	<ul style="list-style-type: none"> Need for further research into therapeutic camp programmes and the components which positively impact outcomes. Further investigation needed into the medical aspects of camp and potential integration with standard clinical care.

Lead author AMSTAR Quality appraisal	Study Designs	Intervention types	Primary findings	Recommendations
Masterton et al., 2016 CRITICALLY LOW	Qualitative examination of need (n=8) Quantitative interventions (n= 4)	Group therapy (n=1) Online CBT (n=1) Educational/supportive retreat (n=1) Psychosexual education (n=1)	Eighteen themes identified which were integral to AYA transition. Needs are highly individualised meaning type of therapy is less significant than therapeutic components.	The most frequently mentioned therapeutic components were education on cancer, coping, sexual identity, maintaining a sense of normalcy, and obtaining AYA support. These five components should be given special credence when considering AYAs' developmental and psychosocial states and determining effective therapies for individual patients.
Plante et al., 2001 CRITICALLY LOW	Total cancer studies (n=17) Designs not specified	Emotional support (n=9) Adaption/Skill development (n=1) Summer camp (n=7)	There have been no well-controlled studies of the psychological impact of emotional support groups with paediatric populations, thus emotional support groups do not meet minimal criteria for empirical validation. Similarly, summer camp interventions did not meet minimum criteria for empirical evaluation.	<ul style="list-style-type: none"> - Need for well controlled, multisite studies into the effectiveness of group interventions. - Cost effectiveness studies are also required to compare individual and group interventions. - Interventions should ensure that measurement tools are reliable and correspond with treatment objectives.

* Quality appraisal is colour coded to reflect the proposed AMSTAR quality appraisal tool scoring system; **Green** = Moderate (more than 1 non-critical weakness), **Yellow** = Low (one critical flaw with or without non-critical weakness), **Red** = Critically Low (more than one critical flaw with or without non-critical weakness).

Bryant, & Cohn, 2012) or psychosocial (Meyler, Guerin, Kiernan, & Breatnach, 2010; Seitz et al., 2009; Walker, Martins, Aldiss, Gibson, & Taylor, 2016) interventions for CAYAs with cancer. While most reviews included only quantitative methodologies, that generally test and compare an intervention group, against a “usual care” or control group, Masterton and Tariman (2016) was the only review to primarily include qualitative methodologies, that generally simply observe the effects of taking part, called non-intervention studies. Only four of their included studies were interventions, though the remaining papers proposed key considerations and intervention components based upon the unmet needs of AYAs with cancer. A number of reviews included studies of non-cancer populations (i.e. chronic illness) and included interventions which were not of interest to this review (e.g. health promotion, symptom reduction, formal therapies). The current review has therefore focused on the sections of these reviews most applicable to the aims of the current study.

Quality assessment scores also varied greatly between studies, ranging from 3/13 (Plante et al., 2001; Masterson & Tariman, 2016) to 11/13 (Ranmal, Prictor, & Scott, 2008; Walker et al., 2016). No study reported on the sources of funding for all included studies, and only three studies (Sansom-Daly et al., 2012; Bradford & Chan, 2017; Ranmal et al., 2008) explicitly indicated that review methods were established prior to conducting the review. All reviews did however include components of PICO in their research questions and all but one study (Meyler et al., 2010) provided key terms or search strategy details in their review.

3.2 Therapeutic recreation camps

The most commonly reported interventions were “therapeutic recreation” or “camp” programmes. Though a great deal of variation exists in both the definition and design of such interventions, they can broadly be characterised as “supportive environments where attendees participate in a range of recreational activities with the goal to impact upon physical, psychological and/or social functioning” (Martiniuk et al., 2014, pg. 778). They are often multi-component interventions, categorised by Meyler and colleagues (2010) as universal rather than targeted interventions to support families and build upon their inherent resilience. While camp interventions rarely include didactic activities or explicit illness related discussion (Plante et al., 2001), the combined elements of group living and activities, alongside time away from day-to-day life stress, appears to foster improved communication, relationship development, and a sense

of agency and independence (Harper, 2017). One review focused exclusively on camp interventions for children with cancer (Martiniuk et al., 2014), while another two examined camps for CAYAs with chronic illnesses inclusive of cancer (Epstein et al., 2005; Moola et al., 2013). Five of the remaining reviews (Sansom-Daly et al., 2012; Walker et al., 2016; Meyler et al., 2010; Plante et al., 2001; Masterton & Tariman, 2016) included or made reference to “therapeutic recreation” or “camp” interventions.

Epstein and colleagues (2005), reported that therapeutic camps offered children a chance to engage in informal discussion about cancer which translated to increased knowledge about their condition. Furthermore, relationships were developed with other campers which lasted beyond the camp experience. Though a number of included interventions appeared to enhance health-related quality of life for attendees, significant methodological weaknesses and inconsistencies between studies limited the reliability of these findings. A subsequent review by Moola and colleagues (2013), aimed at updating the findings of Epstein and colleagues (2005), included six camp interventions for children with cancer. Four of these (Kiernan, Guerin, & MacLachlan, 2005; Török, Kökönyei, Károlyi, Ittész, & Tomcsányi, 2006; Wu, Prout, Roberts, Parikshak, & Amylon 2010; Barr et al., 2010) are detailed in Appendix 1.1 while the remaining two (Békési et al., 2011; Meltzer & Rourke, 2005) appeared to follow largely the same format, with camps lasting 7 (Meltzer & Rourke, 2005) and 8 days (Békési et al., 2011) and featuring activities such as horseback riding, archery, boating, swimming, arts and crafts and team games. Moola and colleagues (2013) similarly noted inconsistencies in how camps were reported, additionally noting that the quality of most studies were weak. Nonetheless, the authors stated that therapeutic camps do appear to offer some, short-term psychosocial benefits to individuals, though it was unclear whether improvements were maintained over time. The authors recommended focusing on reinforcing a consistent “camp philosophy” of inclusion, participation, self-esteem, and independence to drive long-term positive psychosocial change among children.

The role of therapeutic recreation camps in fostering independence was further reflected in the review by Martiniuk and colleagues (2014) who emphasised the opportunities afforded to children with cancer who may be otherwise overprotected by their parents. In the context of children with cancer, the authors highlighted the specific benefits of therapeutic recreation camps on well-being, mood, self-concept, empathy, and friendship, and quality of life. Specifically, camps such as the Barretstown Gang Camp (Kiernan et al., 2005) and Camp Courage

(Török et al., 2006) helped children with cancer and their siblings develop their emotional skills, explore their interests, and promote positive coping behaviours through improved self-confidence. Kiernan and colleagues (2005) in particular, noted positive and lasting improvements in social, practical, and psychological domains following attendance at the ten day Barretstown Gang Camp for children with chronic illnesses, inclusive of cancer. Camping interventions were also reported as providing positive respite for both children and parents (Wu et al., 2010; Meltzer et al., 2004), with Meltzer and colleagues (2004) reporting that camp provided mothers with a break from the stress and challenges of caregiving. Though these changes did not last beyond the intervention, it should be noted that the camp only catered for children with chronic illnesses and not parents. More recent work by Barr and colleagues (2010) examining a therapeutic camp for whole families stressed the relationship between family leisure and positive family outcomes. It may be that respite is most impactful when it offers both parents and children the supportive environment to foster improved family bonds.

Not all interventions in the Martiniuk and colleagues (2014) review reported positive outcomes however, with a number (Brown, 2008; Wellisch Crater, Wiley, Belin, & Weinstein, 2006; Conrad & Altmaier, 2009) reporting little to no change in post-intervention outcomes. Though there remains a lack of investigation into the components of camp interventions most beneficial to children with cancer and their families, the growing prevalence and interest in such interventions reflects their value in meeting the needs of this group (Martiniuk et al., 2014). Prominent camp interventions are detailed in Appendix 1.1.

3.3 Education/Information provision

The second most commonly reported intervention type was education/information provision. Two dominant studies by Canada, Schover, & Li (2007) and Hinds and colleagues (2000) were reported across five and four reviews respectfully, while two computer-mediated interventions (Jones et al., 2010; Kato, Cole, Bradlyn, & Pollock, 2008) were reported across two studies.

The content of interventions again differed significantly, including; sexual development and fertility (Canada et al., 2007), self-care behaviours (Hinds et al., 2000; Kato et al., 2008), cancer and treatment knowledge (Dragone, Bush, Jones, Bearison, & Kamani, 2002; Jones et al., 2010), and coping (Wu et al., 2013). Significant improvements were observed in a number of these interventions (Canada et



al., 2007; Dragone et al., 2002; Jones, 2010; Kato et al., 2008), though two reported little to no impact of the intervention (Hinds, 2000; Wu et al., 2013). Interventions also varied in terms of their content focus, with some providing information alone while others incorporated supportive components alongside education. The Canada and colleagues (2007) intervention, for example, comprised two individual 90-minute sessions around cancer and sexual health. Participants were first provided with information and a “workbook” on the impact of cancer on sexual development and fertility. Following this, the supportive component of the intervention allowed participants to explore the impact of cancer therapy on their sexual identity and peer relations. Similarly, the Wu and colleagues (2013) intervention comprised three components; identification of treatment related stressors, generation of effective coping strategies, and the opportunity to share coping experiences. While participants valued the opportunity to share emotions and experiences with others, no significant improvement in coping strategies relative to controls was observed.

While educational interventions appear promising, there is more to do in terms of establishing their capacity to provide psychological benefits beyond education (Sansom-Daly et al., 2012). As noted by Plante and colleagues (2001), while education-only groups may improve attitudes towards medical services and adherence to treatment they appear limited in improving symptoms. The purpose and added value of educational interventions should be considered prior to their inclusion in broader interventions, with Moola and colleagues (2013) noting little impact of formal education components of therapeutic camp outcomes. Important to note is that information can be empowering for some AYA's and distressing for others (Zebrack & Isaacson, 2012), with Epstein and colleagues (2005) further emphasised that children may prefer informal knowledge sharing with their peers over formal education. While information provision and education is

considered a necessary component of cancer care among CAYAs (Masterton & Tariman, 2015), incorporating these components into broader peer-support interventions may be of greater benefit to patients.

3.4 Peer/Emotional support

Masterton and Tariman (2015) emphasised the key role peer-support plays for adolescents and young adults (AYA's) with cancer, defined as between 13 and 24 years. The authors noted that support from peers who also have cancer is often valued above that of parents and healthy peers. Despite the potential psychological and supportive benefits of peer-support, Plante and colleagues (2001) noted a lack of well-controlled methodologically strong studies aimed at CAYAs with cancer. Though a number of the interventions in the Masterton and Tariman (2015) review included peer support components, only two (Love et al., 2012; Zebrack, Oeffinger, Hou, & Kaplan, 2006) were predicated on this approach.

Love and colleagues (2012) qualitatively examined the impact of an online support forum for young adults with cancer. Speech events, defined as communication aimed at achieving goals related to psychosocial needs, were counted and thematically analysed. Participants exchanged emotional and informational support, coped with difficult emotions through expression, and shared personal experiences of their cancer journey. Participants highly praised the online forum, with the authors emphasising the importance of shared group membership in fostering trust between members. Zebrack and colleagues (2006) combined a four-day cancer retreat "Camp Māk-a-Dream" with an advocacy workshop that aimed to empower and educate young people with cancer. The authors emphasised that engagement with peers who had faced similar challenges provided opportunities to address areas of concern, share life experiences, and develop strategies for successful achievement of personal and social goals. Again, the opportunity to meet other young people and form a community was central to the programme's success with most participants describing the development of new friendships as the most enjoyable part of the experience.

The two most prominent interventions across reviews were Heiney, Ruffin, Ettinger, & Ettinger (1988) and Baider and De-Nour (1989). Neither study showed significant change in psychological functioning over time, though a subgroup of participants from the Baider and De-Nour (1989) study who were no longer in active treatment (n=4) reported a decrease in psychological symptoms. Additionally, though no improvement was measured in the Heiney and colleagues (1988) study, the

support group appeared to have a therapeutic effect in helping adolescents cope with cancer related stressors.

This lack of supportive evidence should not overshadow the value of such approaches. As noted by Seitz and colleagues (2009), a number of support group interventions are present in the literature, though these had not yet been empirically evaluated. Sansom-Daly and colleagues (2012) echoed this issue, further emphasising the methodological flaws in existing peer-support interventions such as a lack of follow-up, non-randomised groups, and varied control groups. Furthermore, many other intervention types, such as therapeutic camp and skill training, incorporate components of peer support in their design. Peer support is built upon the understanding that engagement with those who understand and share in your experience in both psychologically comforting and healing (Plante et al., 2001). While there is a need for more rigorous evaluation of peer-support interventions, their added value within broader interventions is widely recognised. As emphasised by Seitz and colleagues (2009) the therapeutic process of group activities, regardless of their specific aim, can facilitate interactions between peers, reduce isolation, and stimulate new approaches of dealing with issues related to illness. Appendix 1.3 displays the most prominent peer-support interventions identified in the literature.

3.5 Skills training

Skills training is defined by Sansom-Daly and colleagues (2012) as an intervention which includes explicit and often practical strategies for coping with stressors. These authors advocate for the inclusion of skill training components within peer-support and educational interventions, which differ in relation to the expected aims and outcomes. Specifically, they stated the importance of teaching communication skills and including practical elements during and between sessions. Such an approach was argued to not only offer opportunities to share disease-related knowledge and experience, but also to teach ways to identify and change maladaptive thought and behaviour patterns.

Only two studies in the Sansom-Daly and colleagues (2012) review utilised skills training with cancer patients (Hinds et al., 2000; Kazak et al., 2004). The Hinds and colleagues (2000) study, which also fell under the theme of education/information provision, was the most widely reported skills training intervention across reviews. The single session one-to-one coping skills intervention was delivered to forty young people with cancer aged 12-21 years. No significant differences were observed between groups, though the authors posit that the combination

of a lack of power and ceiling effects may have impacted this. While the current review did not include CBT based interventions, the work of Kazak and colleagues (2004) was also highlighted by Meyler (2010) as one of the only interventions to qualify as promising for use with families affected by cancer. The intervention combined CBT and family therapy to improve posttraumatic stress symptoms (PTSS) during a day-long intervention. Despite its brevity, significant reductions in intrusive thoughts among fathers and in arousal among survivors were found in the treatment group.

The next most commonly reported study, Varni, Katz, Colegrove, & Dolgin (1993) was featured in two reviews (Ranmal et al., 2008; Meyler et al., 2010). This intervention combined social skills training, which focuses explicitly on the skills needed for successful social interaction, with a school re-integration programme for children with cancer aged 5-13 years. Participants took part in three individual 60-minute sessions covering social cognitive problem solving, assertiveness training, and handling teasing while control participants received routine school re-integration services. Significant reductions in anxiety alongside improved perceived social support were reported by participants in the intervention group though group differences were not present at the nine-month follow-up.

While a large number of skills training interventions were reported by Plante and colleagues (2001), only one of these was aimed at young people with cancer (Kazak et al., 1999). This intervention also employed formal CBT within a multifamily format, (where several families receive the intervention simultaneously) to reduce anxiety and PTSS. Plante and colleagues (2001) acknowledged skills training as a promising option for promoting positive coping behaviours and improving psychosocial functioning among children with chronic illness. As with peer-support options, interventions specifically designed around skill training among young people with cancer were rare within the included reviews and skills development tended to be incorporated as part of broader interventions. Examples include the studies by Wu and colleagues (2013) and Zebrack and colleagues (2006) mentioned previously, both of which combined aspects of education, peer-support, and skill development among participants with cancer. Appendix 1.4 displays the most prominent skill training interventions identified within the included reviews.

3.6 Intervention characteristics

Across the four prominent themes, the majority of reviews provided minimal breakdown of the characteristics of successful interventions. This was often due to methodological issues, differences between studies (Bradford & Chan, 2017; Epstein et al., 2005; Ranmal et al., 2012; Walker et al., 2016), and inconsistencies in reporting (Moola et al., 2013; Meyler et al., 2010). Two reviews (Masterson & Tariman, 2016; Sansom-Daly et al., 2012) explicitly reported intervention characteristics deemed critical to the successful results, while two others (Epstein et al., 2005; Moola et al., 2013) highlighted select intervention characteristics they subjectively deemed valuable. The most successful or important characteristics identified are highlighted in **Box 4**.

Box 4. Highlighted successful and/or important characteristics of psychosocial interventions

4

- ☺ Therapeutic contact over a longer period of time was a powerful factor in programme success: six or more sessions spanning more than three months appeared more successful
- ☺ Importance of skills training, in particular, communication skills which may be most effective when delivered by psychology or counselling-trained professionals
- ☺ Teaching positive coping strategies as well as improving parent-child communication may leave families better equipped
- ☺ Development of coping skills early after diagnosis was a key characteristic of successful transition from acute care to survivorship.
- ☺ Informal interactions between participants facilitated an exchange of knowledge and experience around cancer
- ☺ Consideration should be given to whether participants want formal education sessions
- ☺ Difficult to discern the contribution of nonspecific (e.g. peer-support) versus specific (e.g. skills training) components, therefore this list provides early indications, rather than definitive suggestions for change.

Sansom-Daly and colleagues (2012) examined psychological interventions for adolescents and adults with chronic illnesses, inclusive of cancer. They highlighted that greater amounts of therapeutic contact over a



A family room in Daisy Lodge.

longer period of time was a powerful factor in programme success. Specifically, interventions with six or more sessions spanning more than 3-months appeared more successful. The authors also stressed the importance of skill training, in particular, communication skills as a means of coping with illness. Such skills training was most effective when delivered by psychology or counselling-trained professionals and allowed participants to learn ways of both identifying and reacting to maladaptive thoughts or behaviours.

While few of the interventions they examined included a parent or family component, those that did appeared to lead to better outcomes. The authors stated that family pressures, such as the developmental challenges of adolescence, may impact the adjustment of AYA's with chronic illnesses. As such, teaching positive coping strategies as well as improving parent-child communication may leave families better equipped to deal with chronic illness. Surprisingly, despite the important role of support from family, Sansom Daly and colleagues (2012) noted that findings from peer-support interventions were inconsistent. The authors indicated that interventions delivered in group were not more likely to show improved outcomes, and that it was difficult to discern the contribution of nonspecific (peer-support) versus specific (e.g. skills training) components to outcomes. However, this likely reflected the limited number of included peer-support interventions ($n=4$) with the authors themselves acknowledging that there is a disconnect between the available and the empirically validated peer-based interventions.

Masterson and Tariman (2016) was the only other review to report important considerations for interventions. Though their review did not focus solely on quantitative studies, the authors did report on the characteristics deemed most important to successful transition from acute care to survivorship. In line with Sansom-Daly and

colleagues (2012), the development of coping skills was one of the key characteristics of successful transition and the authors emphasise the need to promote healthy coping skills early after diagnosis. Both cancer education and peer support were also among the most commonly reported characteristics across the included studies. Cancer education was considered a broad concept, extending beyond disease knowledge to include areas such as life after treatment and sexual development/functioning. As noted within the Epstein and colleagues (2005) review, cancer education does not need to occur in a formal way. As was the case in the Bluebond-Lagner and colleagues (1990;1991) camp studies, informal interactions between participants facilitated an exchange of knowledge and experience around cancer. The authors stated that children will seek information from peers when needed and consideration should be given to whether participants want formal education sessions. Moola and colleagues (2013) also referenced the potential for informal knowledge sharing within therapeutic camps. One of their included studies compared the use of a routine night-time "cabin-chat" to a structured problem-solving intervention around managing asthma (Pulgaron et al., 2010). No difference in outcomes was observed between groups though a trend towards increased asthma knowledge was observed within the "cabin-chat" group. The authors suggest that informal sharing of knowledge and experience between campers may have occurred which contributed to the improvements across both groups.

Although the remaining reviews did not set out to specifically identify the components of interventions that were most influential, we have compiled the most useful impressions expressed within those papers and summarised them below.

The benefits of conducting group based interventions were evident in the review of family based interventions by Meyler and colleagues (2010). While the authors did not set out to identify the most successful characteristics of interventions, they noted that multifamily approaches, where several families receive the intervention simultaneously, are of particular benefit to participants.

While the inclusion of both children and their families in interventions is recognised as being important, Masterson and Tariman (2016) posit that the most important support comes from peers who also have cancer. Such support was also considered central to another proposed key characteristic of cancer interventions; maintaining normalcy. Therapeutic recreation and camp interventions in particular appeared to address this need, often providing an opportunity for independence from parents

who were overprotective of their child (Martiniuk et al., 2014). In addition to skill building and development, such interventions often provided children with cancer a chance to have the same normalising experiences as their healthy peers (Moola et al., 2013). In the context of therapeutic camps, Moola and colleagues (2013) suggested that if normalcy is the goal, interventions should ensure not to encroach upon or compromise this for the sake of intervention efficacy or creating long-term change. In striking this balance, the authors call for greater consideration of the needs and wants of the child with cancer.

A key message across reviews was that CAYAs should have a greater say in the development of interventions. Masterson and Tariman (2016) described this characteristic as a need for individuality, though this could also be described as the need to recognise and incorporate the agency of young people with cancer. As stated by Ranmal and colleagues (2008), young people's preferences for particular interventions may moderate their effectiveness, with some young people unwilling to participate in formal group therapies. Sansom-Daly and colleagues (2012) also recommended the inclusion of youth representatives in intervention development to ensure the appropriateness of interventions. In addition to aiding in intervention development, acknowledging the qualitative experiences of participants may further our understanding of the characteristics considered most beneficial within interventions. A number of reviews (Epstein et al., 2005; Moola et al., 2013; Meyler et al., 2010) emphasised this point, noting the significant lack of qualitative examination of therapeutic camp and family-based interventions. As argued by Epstein and colleagues (2005) both interventions themselves and the measures used to examine them differ significantly between studies. This may not only contribute to the inconsistent outcomes between studies but may also mask many of the subtle yet equally important impacts of such approaches. Moola and colleagues (2013) further suggested that it may be the social support and role-modelling that occurs at camp which mediates psychosocial change. Quantitative and proxy measures may simply not be sensitive to such impacts and thus may underplay or misrepresent the importance of such characteristics. Providing CAYAs with the opportunity to describe their experiences may provide a more enriched description of the intervention and allow for greater comparison between studies (Epstein et al., 2005).

4. Discussion

The following section discusses the results of the review, the implications of these findings and the persistent gaps in existing knowledge.

4.1 Overview

Findings of the current review demonstrate a growing interest and focus on psychosocial interventions for CAYAs with cancer. Specifically, a growing number of studies are testing therapeutic recreation, educational, skill training, and peer support interventions. While three reviews explicitly focused on therapeutic recreation camps (Moola et al., 2013; Martiniuk et al., 2014; Epstein et al., 2005) the remainder broadly examined a range of different intervention approaches. The majority of reviews described their work as focusing on psychosocial interventions (Bradford & Chan, 2017; Seitz et al., 2009; Walker et al., 2016; Sansom-Daly et al., 2012) or group or family based interventions (Plante et al., 2001; Meyler et al., 2010). The remaining two described their focus as interventions to improve communication (Ranmal et al., 2008) and interventions for transition from an AYA patient with cancer to a cancer survivor. It was clear that out of the four categories, therapeutic respite camps appeared most promising in terms of the number of primary interventions with positive outcomes reported in terms of effectiveness. Therapeutic respite camps such as Kiernan and colleagues (2005), Török and colleagues (2006), and Wu and colleagues (2010) reported positive changes in self-esteem and self-efficacy, improved peer relations and the development of lasting friendships, and improved knowledge around cancer and its treatment. However, a lack of intervention replication, disparate approaches to intervention delivery, and a lack of focus on the specific intervention characteristics most impactful on outcomes limits the degree to which these findings can be generalised to other contexts. A small number of intervention characteristics which appear to positively impact upon outcomes were also noted. Greater therapeutic contact, inclusion of family members, a focus on communication skills and informal knowledge sharing, and participant driven intervention design were recommended within reviews.

Though reviews often commented on the methodological and design issues prominent within primary literature in the area, quality appraisal scores for several included reviews were also below the expectations of standardised academic research. Seven out of the eleven reviews scored critically low on the AMSTAR and only three reviews explicitly

indicated that their methods were established prior to commencing the review. Inconsistencies in the depth of reporting and the detail provided on primary intervention studies were also apparent. Plante and colleagues (2001), for example, reviewed 125 group interventions for paediatric chronic conditions. Of these, seventeen were focused on individuals with cancer, though very few of these were described in any detail, most likely due to overly broad scope of investigation. In addition to recognising the shortcomings of individual research studies, it is also necessary to critique the rigor and quality of those studies reviewing the area. Inadequate and inconsistent reporting restricts the ability to extract useful and generalizable information that can be directly translated to practice. Put more simply, sometimes there is not enough information provided to allow for development and delivery of equally effective services, such as the qualifications and experience of the facilitator, which was often missing.

While clear quality issues were apparent within a number of the included reviews, the level of detail required by the AMSTAR review tool should also be noted. This tool proved a comprehensive and useful method of appraising review studies, however the current recommended scoring system was found to be overly restrictive. In designing the tool, Shea and colleagues (2017), recommend scoring reviews as high, moderate, low, or critically low depending on the number of critical and non-critical weaknesses identified. When this method was applied in the current work all studies bar one Cochrane review (Ranmal et al., 2008) scored “low” (one critical weakness with or without non-critical weaknesses) or “critically low” (more than one critical weakness). If the authors failed to include a list of the excluded studies as well as a justification for their exclusion, that constituted a critical weakness. So too did failing to report that the review question, search strategy, inclusion/exclusion, and risk of bias assessment



The upstairs lounge in Daisy Lodge.

was established prior to commencing the review. Essentially the evidence reflects a research area in a relatively early stage of development, in terms of academic rigour. However, we have uncovered many useful and relevant results that can inform practice, and can certainly inform future research that could be carried out as part of the CFC-QUB collaboration. The following sections discuss these findings.

4.2 Therapeutic camps

Despite these quality issues, common intervention themes and observations emerged across reviews. Among the most prominent interventions were therapeutic recreation camps, with Martiniuk and colleagues (2014) highlighting the positive impact of camp on quality of life, friendship, emotional well-being, and mood. Both Moola and colleagues (2014) and Epstein and colleagues (2005) further re-iterated the potential positive impact of therapeutic camps on psychosocial outcomes and QOL. Such interventions were limited however, with the short length of camp interventions potentially impacting their ability to create lasting improvement. Individual camp interventions also varied greatly in their design and activities, with Plante and colleagues (2001) acknowledging that camps often contain components of emotional support, psychoeducation, and skill development. This often broad focus and lack of didactic activities poses an issue when examining outcomes. At present, there is insufficient literature to establish how the individual components of such interventions contribute towards positive outcomes. There is a need for more rigorously designed and controlled trials of these interventions, that ensure all components, procedures and personnel involved in the delivery are adequately reported on.

4.3 Education/Information provision

Supportive evidence surrounding educational interventions appeared more mixed than for therapeutic respite camps. Individual interventions again varied significantly, covering topics from sexual development to self-care, with varying degrees of effectiveness reported. As stressed by a number of reviews (Moola et al., 2013; Epstein et al., 2005; Masterson & Tairman, 2015) while there are clear education needs within this population, it is necessary to consider the added value of formal education for young people with cancer. Individuals may prefer seeking information independently, and interventions should consider fostering an environment where informal education and knowledge sharing can occur. The information needs of CAYAs can also differ dramatically, depending on factors such as their age,



One of the playrooms in Daisy Lodge.

or stage of treatment. The most widely reported and robust educational intervention was that of Canada and colleagues (2007). This intervention sought to address gaps in knowledge around sexual development and fertility with significant improvements in knowledge and reductions in concern and body dissatisfaction noted among participants. Masterson and Tariman (2016) also drew attention to the challenges around sexual identity and fertility experienced by young people with cancer. In addition to education around treatment, self-care, and coping, there appears to be a clear need for more targeted and comprehensive education on cancer and sexuality. In summary, both the content and delivery mechanisms for educational interventions are in need of development and further research.

4.4 Peer/emotional support

While two included reviews (Seitz et al., 2009; Plante et al., 2001) noted a lack of investigation into such approaches, peer/emotional support appears both desired and beneficial for CAYAs with cancer (Masterson & Tariman, 2015; Sansom-Daly et al., 2012). Interventions studies such as Love and colleagues (2012) and Zebrack and colleagues (2006) emphasised that in addition to the emotional benefits of peer support, such approaches may also foster information sharing, empowerment, and social integration. Often studies employing therapeutic camp or skill training interventions also included peer/emotional support components. As highlighted by Sansom-Daly and colleagues (2012), this makes it difficult to discern the relevant contributions of each separate component. Despite widespread recognition of the need for and value in engaging with peers who share in your experience, empirical investigation into peer support interventions is lacking. In summary, while peer support is valued and recognised as a complimentary component of other supportive interventions, there is a need for further

evaluation and testing, focused on the value and benefits of peer support for this vulnerable population.

4.5 Skills training

Despite their inclusion in a number of reviews, few skills training interventions were aimed at young people with cancer. Within the included reviews, Sansom-Daly and colleagues (2012) stressed the importance of developing communication skills as a means of coping with illness. Acknowledging the views of Sansom-Daly and colleagues (2012), Walker and colleagues (2016) stressed however that the disparity between currently available intervention designs limits these conclusions. While communication skills are valuable both for empowering individuals with cancer and facilitating their engagement with peer and family support, evidence for the effectiveness of skills training was mixed. In summary, future research efforts should focus on furthering our understanding of how to deliver skills based training (e.g. group or individual), in what format to deliver (e.g. face-to-face/web based), and using what approach (e.g. skills based/reflective methods) in order to find out what is best suited to improving outcomes for CAYAs with cancer.

4.6 Intervention characteristics

Few reviews explicitly commented on the characteristics of interventions considered most impactful on outcomes. Those that did, advocated for the inclusion of five characteristics;

- A parent or family component (Meyler et al., 2010; Sansom-Daly et al., 2012)
- More/longer therapeutic contact (Sansom-Daly et al., 2012)
- A focus on coping and communication skills (Sansom-Daly et al., 2012),
- Recognition of the value of informal knowledge and skill sharing through peer-interaction (Moola et al., 2013), and
- Participant input into the design of the service or intervention (Ranmal et al., 2008; Epstein et al., 2005).

While these findings are helpful in informing future interventions, it is clear that significant gaps in knowledge exist surrounding what works and why. To address this, future studies should provide more explicit and descriptive detail on their intervention designs and procedures. Furthermore, in line with the recommendations of (Moola et al., 2013; Sansom-Daly et al., 2012; Walker et al., 2016)

grounding interventions in theory may help push authors to consider what elements of their intervention are expected to affect change on what outcomes.

Importantly, qualitative methods may offer insight into the intervention characteristics most valued by service users. The need for a more mixed methods approach to intervention evaluation was reiterated across several reviews (Ranmal et al., 2008; Epstein et al., 2005; Sansom-Daly et al., 2012; Meyler et al., 2010; Masterson & Tariman, 2016). Recognising the value of service users as active agents in their own treatment also appears to be key to the effectiveness of interventions, suggesting co-production methods of service development would be a useful way to advance the knowledge base.

In addition to highlighting characteristics of interventions for consideration, several key areas of need also developed from the literature. In particular, the work of Masterson and Tariman (2016) emphasised the needs of young people with cancer in the areas of; education, coping skills, peer-support, family engagement, individuality, and normality, among others. While reviews such as Sansom-Daly and colleagues (2012), organised interventions by design (educational, skill based, peer-support), categorising and comparing interventions by the needs they address may be useful for future reviews. Interventions in the current review often overlapped in terms of intervention characteristics, making it difficult to neatly fit them into a single category. Furthermore, as was the case with educational interventions, comparing across individual studies was not always appropriate given differences in aims and focus. Approaching intervention design and evaluation from a needs based perspective may help in addressing some of the disparities in effectiveness across interventions.

As stated by Walker and colleagues (2016), most included studies employed multiple measures of effectiveness without a clear primary and secondary outcome. This again eludes to a lack of consideration of specific needs being identified and addressed. Meyler and colleagues (2010) further noted, in reference to family-based psychosocial interventions, that many included studies appeared to reflect once off attempts to address gaps in the literature. In summary, the growing interest in this area, and the growing recognition of the value of psychosocial interventions for young people with cancer, will help to encourage researchers and practitioners to support more detailed, higher quality, theory and needs driven, and replicable research.

4.7 Limitations

The current review was limited by the disparity across review studies. Despite broadly similar aims and inclusion criteria, the included primary intervention studies were not all similar enough for meaningful comparisons to be made. This could be related to the varied terminology used in this area. Terms such as CAYA which is relatively recent in the literature, and psychosocial well-being which is broad enough to be interpreted and defined in multiple ways, impacts on all aspects of reviews, from searching to concluding. Differences in the depth of reporting also limited comparability between reviews, with a noted lack of consistency in how the population, intervention, comparator (control groups), and outcomes were described.

A second limitation relates to the scope of the current review which excluded reviews of formal (CBT, family therapy) and complementary (yoga, aromatherapy) therapies. Though some reviews included primary studies of this type, the reviews were only included if the primary focus was non-formal, supportive interventions. The current review was therefore not exhaustive in capturing all non-formal interventions for CAYAs with cancer. Some promising interventions that contain informal psychosocial support as a secondary component of an intervention may not be captured within this work.

Thirdly, included reviews were often limited in their ability to draw meaningful conclusions due to the significant methodological and design issues within their included primary studies. Common across several reviews were calls for more rigorous and large scale interventions which would aid in the generalisability of findings. In line with this, it is important to highlight the range of quality appraisal within included reviews. The reliability and validity of these reviews would ideally be stronger, if they were to form the basis of a change in evidence-based services.

5. Review Conclusions

5.1 Strength of the evidence

There is growing interest and investigation into interventions for CAYAs with cancer. A number of important findings have been revealed that are directly relevant to the work of CFC. It is recognised that the needs of this group are often complex and dependent on factors such as their stage of treatment. Nonetheless, overarching needs around education, coping skills, peer support, family engagement, normalcy, and agency, were identified. Further to this, a number of non-formal intervention approaches emerged which aim to tackle some or many of these needs. Specifically, therapeutic respite, educational, peer support, and skills training interventions were most commonly reported across reviews. These categories were also not always mutually exclusive, with characteristics of interventions often overlapping between categories.

While a number of individual interventions appeared promising, inconclusive and mixed evidence limited the ability of reviews to explicitly recommend any one particular approach. The strongest evidence comes from three reviews focused on therapeutic camp interventions. It indicated a growing interest in and recognition of the need for these residential approaches to supporting CAYAs diagnosed with cancer.

5.2 Gaps in the evidence

Several gaps and issues pertinent to future research have been identified and are listed in Box 5 Gaps to be addressed in future research. It is necessary to acknowledge young people as active agents, capable of communicating their needs and making decisions around their care. In attempting to better understand what interventions work and why, greater weight should be given to the voices of those being targeted. The need for examining peer-designed and peer-delivered interventions lends itself to the use of co-production research and evaluation methods. While attempts have been made to examine the characteristics of interventions most impactful on

outcomes, this was often also limited by the design and detail provided by primary studies.

There is a need for interventions to be more explicit in reporting the underlying needs they aim to address and the underlying characteristics of their intervention (peer support, education, skill development) which seek to achieve this. Interventions should reflect on the added value of individual characteristics for participants and consider employing a more theory driven approach to intervention design.

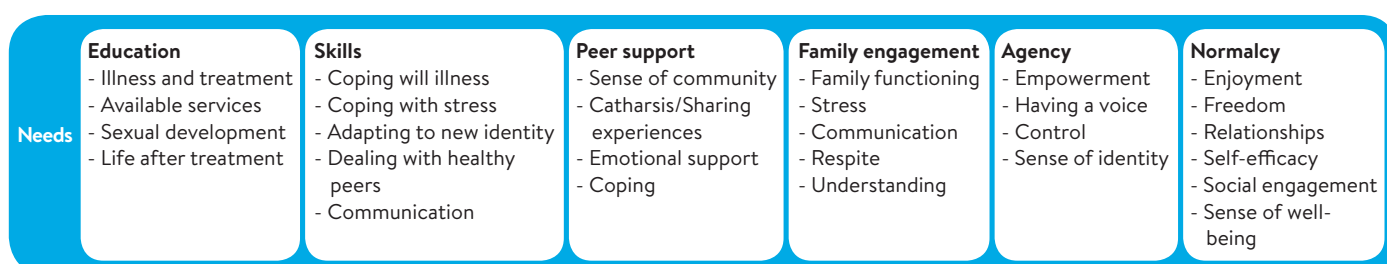
Box 5. Gaps to be addressed in future research

5

- ✓ Prioritising the needs of CAYAs diagnosed with cancer, based on the patient voice
- ✓ Consideration of support needs by age and stage of treatment
- ✓ Co-produced peer designed and peer delivered programmes
- ✓ Needs assessments should be mapped to components of the intervention or service
- ✓ Use of a theory of change or logic models which show how the intervention is expected to work
- ✓ Components of intervention should be well designed and articulated to allow for replication studies
- ✓ Mixed-methods evaluations are needed, including interviews to capture lived experience
- ✓ Deeper consideration of measuring outcomes would strengthen the evidence of effectiveness
- ✓ Rigorous larger scale studies that consider longer term outcomes are required

Several included reviews also noted significant issues around the measurement of outcomes within studies. The inclusion of too many outcome variables increases the risk of type 2 error and limits the generalisability of intervention findings. Further to this, several review studies pointed to

Figure 2. Mapping Process – Areas of Need



a lack of qualitative investigation around interventions for CAYAs with cancer. The lack of well controlled interventions with adequate sample sizes significantly limits the generalisability of intervention studies in this area. While large scale randomised control trials are not always feasible or practical, adopting a more longitudinal approach may help further our understanding of the potential for long-term change.

Box 6. Key conclusions of the review

6

- ✓ Psychosocial interventions for CAYA's with cancer fell into four broad themes; therapeutic recreation, educational, skill training, and peer support.
- ✓ Interventions sought to address a number of key areas of need for CAYA's;
 - Education
 - Skills
 - Peer-support
 - Family Engagement
 - Agency
 - Normalcy
- ✓ Therapeutic respite camps were the most commonly reported and most positively reviewed interventions. Draft
- ✓ Many interventions combine aspects of the above themes making it difficult to conclude what specific characteristics impact positive outcomes.
- ✓ Characteristics that do appear to improve outcomes are;
 - Greater amounts of therapeutic contact
 - Family involvement
 - A focus on coping and communication skills
 - Informal knowledge sharing
 - Participant driven intervention design
- ✓ While there is growing interest and investigation into therapeutic respite camps, research in the area is underdeveloped and gaps exist in the academic literature.

6. Mapping the literature to current practice in Cancer Fund for Children

The current section details the results of the mapping process used to relate the review findings to the work of Cancer Fund for Children (CFC). The section begins with an introduction to the mapping process alongside the steps taken to relate findings to six services provided by CFC; Family Short Breaks at Daisy Lodge, Family Group Work at Daisy Lodge, Young Adult Group Work at Daisy Lodge, Residential Work at Narnia, 1:1 Ward Support for a Diagnosed Child, and 1:1 Community Support for a Diagnosed Child. Primary areas of overlap between the academic literature and CFC services are then described, followed by the challenges of the mapping process, areas for development, and recommendations. To aid in clarifying between the academic literature and the work of CFC the term “intervention” will be used in relation to research studies while “services” will refer to the work of CFC.

When considering the findings of the mapping, it is necessary to acknowledge the differences between interventions identified in the literature and the services

currently provided by CFC. CFC engages in a wide range of person-centred activities aimed at supporting CAYAs with cancer and their families. This support ranges from financial to therapeutic, and from the ward to the community. The breadth of work carried out within each individual service is also extensive and often highly tailored to the needs of the service user. This creates a significant challenge when attempting to map the available literature directly on to the work of CFC. As noted, interventions are often not described significant detail. While clear parallels were found, no interventions described and tested in the academic literature approached the level of comprehensiveness of the services provided by CFC. Furthermore, while evidence is developing, interventions similar to those of CFC remain relatively under-researched. This in itself is a key finding and highlights both the unique and pioneering nature of the work of this organisation. An essential next step, reiterated in the recommendations below, is the refinement and evaluation of these services which may inform the work of similar organisations globally.

6.1 Mapping process

The mapping process was carried out with the assistance of the CFC steering group, a wider group of CFC’s



The children's playground at Daisy Lodge.

Cancer Support Specialists and researchers from Queen's University Belfast.

The following mapping steps were taken upon completion of the review;

1. The findings of the review were circulated including key areas of need and recommended intervention characteristics.
2. Key areas of need identified within the literature were synthesised (figure 2) to aid in the mapping process
3. Extraction forms designed for the systematic review were modified and used by CFC's Cancer Support Specialists and the CFC Steering Group to summarise six of their primary services. Each form provided details of
 - aims,
 - target population,
 - discipline of facilitators,
 - procedure and setting,
 - target outcomes and impact on service users.
4. Six summary documents were produced describing the following services;
 1. Family Short Breaks at Daisy Lodge
 2. Family Group Work at Daisy Lodge
 3. Young Adult Group Work at Daisy Lodge
 4. Residential Work at Narnia
 5. 1:1 Ward Support for a Diagnosed Child
 6. 1:1 Community Support for a Diagnosed Child
5. At a meeting, the steering group discussed the six summary documents, identifying and discussing areas of overlap. Services were then mapped to the literature in terms of the areas of need addressed and the evidence based intervention characteristics.
6. Draft tables were then developed for later refinement.
7. Researchers from Queen's University Belfast later refined the tables and sections added detailing the evidence base supporting each approach, current methods of service evaluation by CFC, and potential alternative methods of evaluation.

The results of this mapping process are displayed in the following sections, 6.2 – 6.7.

6.2 Family Short Breaks at Daisy Lodge

Overview

Set in a purpose built therapeutic centre, short breaks at Daisy Lodge offer respite care for families of CAYAs with cancer. Over 3 days, families can choose to engage in a range of activities including; individual support, individual family work, group work sessions (multiple-families), and complementary therapies. Families can also avail of passes for the local swimming complex or nearby cafés.

Participants

Families of CAYAs (<24 years) who have been diagnosed with cancer.

Families where a parent of a child (<24 years) has been diagnosed with cancer.

The service is inclusive of siblings and CAYAs, parents, carers with confirmed cancer.

Needs addressed by service

- Family engagement
- Peer support
- Agency
- Normalcy
- Skill development (communication skills)

Evidence based components

- Inclusion of family members.
- Families are given time alone together away from home environment.
- Programme contains high degree of choice. Participants lead and directed activities.

Areas of evidence based practice

The therapeutic respite care provided through Family Short Breaks in Daisy Lodge employs a number of evidence based practices recommended in the literature. The value of including family members in therapeutic care was stressed by both Sansom-Daly et al., (2012) and Meyler et al., (2010). Daisy Lodge not only includes family members but offers opportunities for informal peer-support and interaction with other families experiencing cancer. This approach is again grounded in evidence which suggests such peer-support may contribute towards informal knowledge sharing and coping strategies (Moola et al., 2013; Zebrack et al., 2006). Research suggests that this approach to family support may also strengthen family communication and functioning. In line with the recommendations of Ranmal et al., (2008) and Moola et al., (2013) families themselves dictate the design and intensity of the programme. Families are given the choice of participating in activities or spending time by themselves (passes are offered for local recreational activities).

Where this service extends beyond other interventions is in creating a restorative environment for CAYAs and their families. Characteristics such as the standard of accommodation, the quality of food, the on-site services (massage therapy, sauna), and the setting for Daisy Lodge (overlooking the Mourne mountains), undoubtedly contribute to creating a restorative atmosphere for service users. Though such aspects did not feature in the literature quotes from CFC service users reflect the key role these characteristics play in improving outcomes;

"It's the most therapeutic place, the most wonderful happy place I don't know how to thank you guys enough for everything you do for families like ours. It means the world to us. We would never have been able to experience anything like it."

"Cant thank the staff enough.....you are all magic-staff amazing.....pampered, and listened too.....food out of the world.... what a beautiful place with wonderful people"

Service evaluation carried out by CFC

6.3 Family Group Work at Daisy Lodge

Overview

As part of the therapeutic short breaks (described in Section 6.1), Daisy Lodge offers creative group workshops for families. These workshops, facilitated by therapeutic specialists (e.g. Qualified Music Therapist or Community Psychiatric Nurse), may involve music, photography, and arts and crafts. While activities are designed to be engaging and fun, the therapeutic components remain the central focus. Emphasis is placed on family communication and cohesiveness, helping individuals express and share their thoughts and emotions.

Participants

Family groups generally compose the child with cancer, alongside one or two siblings/parents.

Needs addressed by service

- Family engagement
- Peer support
- Agency
- Normalcy
- Skill development

Evidence based components

- Inclusion of family members.
- Activities are facilitated by a trained specialist.
- Focus on development of coping and communication skills.

Areas of evidence based practice

As with the camping intervention of Barr et al., (2010) family group work at Daisy Lodge centres around the use of fun, engaging, and creative activities to support family cohesion and functioning. The design of this service again follows much of the evidence based recommendations of the academic literature. As recommended by Sansom et al., (2012), all activities are led by trained professionals, including; therapeutic specialists, music and art therapists, and youth development workers. Furthermore, activities seek are designed around the use of communication skills, emotional expression, and shared family experiences. The focus on communication skills in particular aligns with the evidence base and the family led approach of the work at Daisy Lodge mirrors the recommendations of both Meyler et al., (2010) and Sansom-Daly et al., (2012).

As was mentioned in the previous section, engagement with other families experiencing cancer has the added benefit of fostering informal knowledge sharing and coping skill development. While some of the interventions examined in the literature included formal education provision, evidence suggests that the Daisy Lodge approach of fostering opportunities for informal knowledge sharing may be of more benefit to CAYA's and their families.

A key difference between the current service and similar camp interventions in the literature is the focus on therapeutic components within all activities. While the majority of "therapeutic respite camps" examined in the literature discuss activities such as archery, arts and crafts, and boating, the family group work at Daisy Lodge designs each activity with a clear therapeutic goal. This is highly novel for such a service and has the potential to affect lasting change in family outcomes. Evident from the experiences of service users were the coping skills developed through these therapeutic activities. As described by one service user *"WE feel more together as a family after our short break, beautiful place, facilities amazing and great staff who were on hand to help us express how we feel after the loss of our son"*.

6.4 Young Adult Group Work at Daisy Lodge

Overview

Aimed specifically at young adults (aged 18-25 years), this service seeks to offer four to five semi-structured group work sessions over a three day short-break. As with the family group work, young adults can participate in a range of activities including; self-care workshop, mindfulness, photography/arts and crafts, and complimentary therapies. Supported by a range of trained therapeutic specialists, focus is placed on reducing isolation and stress, fostering resilience, and providing opportunities for peer support.

Participants

Young adults aged 18-25 years both in-treatment and post-treatment for cancer

Needs addressed by service

- Peer support
- Normalcy
- Agency
- Skills (coping with illness, communication)

Evidence based components

- Opportunities for engagement with individuals with similar conditions
- Group work is facilitated by trained specialists
- Activities focus on developing self-care and coping skills.

Areas of evidence based practice

A key evidence based component of the young adult group work at Daisy Lodge is the combined focus on peer-support and creating a sense of normalcy. Similar to the CAYA advocacy camp of Zebrack et al., (2006), this service provides opportunities to meet and develop friendships with other young adults whilst also seeking to develop useful skills for coping with illness. Such peer-support is critical to young adults both emotionally and in terms of the knowledge and skills sharing which occurs through informal discussions and the sharing of experiences. While the Zebrack et al., (2006) intervention was more formal in organising seminars and educational workshops, the work at Daisy Lodge places greater emphasis on creating a supportive environment for young people to engage through. In line with the evidence base, this participant led approach acknowledges the agency of individuals and may produce better outcomes compared to more formal or rigid approaches. While aspects of the group work at Daisy Lodge seek to support young people in expressing and communicating their emotions and experiences of illness, in line with the recommendations of Moola et al., (2013), the service ensures not to compromise its goal of providing normalising experiences. To this end, the service ensures the enjoyment of participants whilst also providing therapeutic support.

This service is also highly novel, as no other intervention combined aspects of peer-support, skill development, and normalcy/agency in this way for young adults of this age group. In particular, there is a notable gap in the research base surrounding peer-support interventions for CAYA's with cancer. There is potential for the young adult group work at Daisy Lodge to set an example for best practice for other services in the area. To achieve this, further evaluation and assessment of the service is needed using both quantitative and qualitative methods.

Service evaluation carried out by CFC

6.5 Residential work at Narnia

Overview

Located on the same site as the Daisy Lodge facility, the Narnia log cabin offers separate group living accommodation specifically for children and adolescents with cancer. Designed to mimic the feeling of being at a camp, residential group work at Narnia allows children and adolescents experiencing cancer to live alongside one another over a period of three days. Attending children and adolescents participate in a range of adventure learning activities, creative group work sessions, group discussions, and reflective debrief. Activities are designed with the therapeutic goals of building confidence, increasing resilience, and enabling young people to express and reflect on their personal cancer experience.

Participants

Age specific (8-11 years & 12-17 years) children diagnosed with cancer

Group size 8-16

Needs addressed by service

- Peer support
- Normalcy
- Agency
- Skills (coping with illness, communication)

Evidence based components

- Opportunities for engagement with individuals with similar conditions
- Group living experience combining normalcy and informal peer-support.
- Activities focus on coping with illness and emotional resilience.

Areas of evidence based practice

As with the young adult group work at Daisy Lodge, the residential work at Narnia focuses on facilitating peer-support whilst also fostering a sense of agency among service users. Similar to the activity camps of Kiernan et al., (2005) and Bluebond-Langer et al., (1991), and in line with the recommended evidence based practice, the work at Narnia allows young people to meet and engage with others their age who have experienced similar illnesses. Opportunities for informal knowledge sharing and peer support are fostered through the shared living environment and group activities which run over the 3 days. As recommended by the academic literature, focus is placed on communication and coping skills with staff supporting service users to better express their thoughts and emotions. The added value of using trained practitioners in service delivery is also supported by the research evidence base and helps ensure a consistent therapeutic focus throughout all activities.

In contrast to other therapeutic respite interventions in the literature, all activities undertaken within the residential group work at Narnia have a clear therapeutic focus. While no formal skill training or education is provided, in line with the recommendations of Zebrack and Isaacson (2012) and Epstein et al., (2005), the intervention supports and fosters communication and experience sharing between participants. This is a novel approach for interventions of this type and should be further evaluated. While other interventions in the area appeared to only engage in activities such as archery, boating, or arts and crafts, service users leaving Narnia benefit from gaining skills they can carry with them in daily life. As noted by one CFC service user “...it allowed and encouraged us to speak to each other. It is easier because we then know each other. We could talk about our own experiences, how we have changed from being here.”

Service evaluation carried out by CFC

6.6 1:1 Ward Support for a Diagnosed Child

Overview

A Cancer Support Specialist from CFC meets with and supports the child or young person in hospital following admission. Session one involves the development of a therapeutic support plan (to be delivered over 4 sessions in the first instance) in partnership with the child and their parent. Support plans are highly individualised to the participants' needs and are reviewed regularly as per the child's medical treatment plan. Activities may include exploring the impact and meaning of the cancer diagnosis and treatment for the child, supporting the recognition and expression of emotions and feelings regarding illness, and fostering self-esteem and confidence during the cancer journey. Support specialists also act as advocates for participants in the wider hospital setting within the multidisciplinary team involved in their direct medical care. By feeding into larger multi-disciplinary support teams, the CFC support worker can advise on the specific needs of the child and their parents.

Participants

Child or young person diagnosed with cancer up to 24 years.

1:1 hospital-based intervention during an inpatient treatment phase.

Needs addressed by service

- Advocacy
- Skills
- Agency
- Education

Evidence based components

- Highly tailored support
- Focused on the needs of the patient
- Emphasis placed on coping skills and post-diagnosis identity.

Areas of evidence based practice

Ward support was highly novel as a service, combining advocacy and support for children and young people with cancer during their stay in hospital. No intervention identified in the literature sought to address the needs of children and young people in hospital, despite the clear informational, coping, and support needs at this stage. The service is highly tailored to the needs of its users and based upon a background assessment and support plan. In line with Masterson and Tariman, (2016) the agency of service users is respected, with specialists allowing individuals to dictate their own needs and desires. Supporting a child or young person in regaining control of their environment is a key step in helping maintain normalcy during such a difficult time.

Though no direct education or training is provided, advocates work with multidisciplinary clinical teams to direct the provision of education and support based upon the needs of participants. Surprisingly, this type of advocacy work was not featured in the academic literature. Given the overwhelming life changes that occur following diagnosis, alongside education and skills training, there is clear potential for interventions designed around advocating for the needs of the child or young person. It must be stressed that despite its absence in the literature, there is a recognised value in such a service. As described by the parent of one service user “*Our son loved seeing his Specialist visit and he built up a great relationship with her. He struggled with isolation during treatment and seeing his Specialist provided him with a welcome distraction ... Cancer Fund for Children have been an invaluable form of support for our family during treatment.*” The acknowledged need for such a service, coupled with the novel approach employed by CFC indicates that future research and evaluation into this service should be considered a priority.

Service evaluation carried out by CFC

6.7 1:1 Community Support for diagnosed child.

Overview

As with the ward-support, this 1:1 service involves the development of a therapeutic support plan for a child or adolescent diagnosed with cancer. The support is usually developed on the basis of providing six sessions. The plan is highly tailored, developed in partnership with the child and parent, and reviewed mid-way to ensure needs are being met. While the child remains the focus of this intervention, Cancer Support Specialists will often also work with and support both the parents and families of the child. This may also involve signposting and referring families to other services within CFC and also other community based support outside of CFC services.

Participants

Child or young person diagnosed with cancer up to 24 years.

1:1 community intervention within the child's home (to manage infection control).

Needs addressed by service

- Advocacy
- Education
- Normalcy
- Skills (coping with illness/stress)
- Family engagement

Evidence based components

- Highly tailored service.
- Engagement with the wider family.
- Provision of education and relevant information

Areas of evidence based practice

The 1:1 work with children in the community revolves around providing advocacy for and supporting the agency of a child with cancer. As noted previously, there was a surprising gap in the literature surrounding interventions which provide advocacy for CAYAs with cancer. To this end, the community support service of CFC is extremely novel in its approach.

The highly personalised and tailored nature of this service closely aligns with the best practice recommendations of Sansom-Daly et al., (2012), Moola et al., (2013), and Masterson and Tariman, (2016) in allowing service users to communicate their needs and direct their care. As with the 1:1 ward support, this intervention does not provide formal skills training or education, but signposts and supports children in their transition through services. The clear benefits of this service were routinely noted by the parents of service users;

"Our daughter loved her time with the Community Specialist. She got so much from the individual sessions at a time when she was confused and isolated. She was able to talk about her worries and concerns to someone outside of the family."

"Our daughter really benefitted from her one to one work with her Cancer Fund for Children Specialist. Even her teacher noticing the difference in her confidence. The support has been a real life line and made a real difference."

"Our Cancer Fund for Children Community Specialist has provided our son with amazing one to one support during his cancer treatment. She used inventive ideas, such as making volcanoes to discuss emotions etc."

Given the setting of this service (child's home) it was clear that the support provided often extends to family members. This inclusion of family members may aid in promoting healthy coping behaviours in the child whilst also providing supportive benefits to parents themselves. As noted by one parent *"The service was invaluable to us as a family. Our daughter's cancer impacted on each of our four children in different ways. Our Community Specialist advised, assisted and enabled our family to deal with this and ensure the recovery. As a family we have been able to process and recover emotionally from the traumatic impact. Through individual support our children have an awareness and understanding of the impact and the legacy of the experience and how it shapes us a family. We are more confident and able in our ability to continue in our recovery."*

As with the ward support service, there is a clear and critical need for future research and evaluation into this service.

Service evaluation carried out by CFC

7. Implications for Cancer Fund for Children

Results of the mapping process highlighted a number of considerations for CFC. The following sections will detail the main findings, the challenges involved in this mapping process, areas for development within services, and potential future research.

7.1 Areas of overlap

Evident from the mapping process was the high degree of evidence based support for the services provided by CFC. In particular, both the Family Group Work and the Residential Work at Narnia employ a number of evidence based components in addressing the needs of CAYAs with cancer. The three most prominent evidence based characteristics across services were; family involvement, peer-support, and agency/individuality. The importance of these characteristics were repeatedly stressed in the academic literature and represent core components of CFC services.

7.1.1 Family Involvement

The incorporation of wider family members within services is acknowledged as positively impacting outcomes (Meyler et al., 2010; Sansom-Daly et al., 2012). The Family Short Breaks and Family Group Work services reflect the reciprocal importance of family functioning on the coping of the young person alongside the potential impact of the young person's illness on family functioning (Rait et al., 1992). Both services, within a broader therapeutic respite service, additionally provide opportunities for normalising family experiences. Allowing time away from the stresses of home and hospital life is particularly important in helping families cope more effectively with illness (Martiniuk et al., 2014). The work at Daisy Lodge is particularly beneficial in not only offering opportunities for family group work, but in allowing and supporting families who wish to just spend time together. The inclusion of family members also offers opportunities for parents and siblings to access peer-support and share their experiences with other families. Kazak and colleagues (2004) emphasised the need for such support, particularly among fathers, who may not otherwise have an opportunity to engage with other parents who share in their experiences.

7.1.2 Peer-Support

Peer-support is a central component in a number of CFC services. Particularly within both the Young

Adult Group Work and the Residential Work at Narnia, group discussion and peer-engagement are routinely encouraged. Numerous articles within the Masterson and Tariman (2016) review have highlighted peer support as a key need among young people with cancer. In addition to diminishing isolation and loneliness, it can greatly aid young people in sharing their experiences and developing their own narratives around their illness (Zebrack et al., 2006; Love et al., 2012). As recognised in feedback to CFC, such experiences can be highly cathartic and empowering. Masterson and Tariman (2016) argued that this support from peers who also have cancer may be more important than that of the family or healthy peers. As further highlighted by Epstein and colleagues (2005), peers who share in your experiences may also act as a source of information and advice, and may be more beneficial than formal education. Despite acknowledgement of the importance and potential benefits of peer-support (Seitz et al., 2009; Sansom-Daly et al., 2012; Bradford & Chan, 2017), there was a marked lack of well-controlled studies in the literature (Plante et al., 2001). While there is a clear need for more evidence supporting its effectiveness, the use of peer-support within CFC services addresses a clear and salient need among CAYAs with cancer.

7.1.3 Agency/Individuality

In line with the recommendations of Sansom-Daly and colleagues (2012) all services are facilitated by trained specialists with a diverse range of expertise. Further to this, across all services provided by CFC, approaches are tailored to the needs of participants. Families are offered the choice of taking part in group work activities or simply enjoying the short break together. Equally, CAYAs both on the ward and in the community have full control over the direction of their 1:1 support sessions. Though neither service (1:1 Ward Support, 1:1 Community Support) closely matched the interventions found in the literature, their value to service users was evident. The importance of incorporating the views and preferences of young people has been echoed across a number of reviews (Ranmal et al., 2008; Sansom-Daly et al., 2012; Masterson & Tariman, 2016), with Ranmal and colleagues (2008) arguing that recognising young people's preferences and tailoring appropriately may moderate the effectiveness of interventions. As further stressed by Masterson and Tariman (2016), the needs of young adults with cancer can differ significantly depending on their age and stage of treatment. Though few studies have explicitly focused on the impact of individuality and agency in intervention success, there was clear recognition that in order to accurately evaluate the impact of a service, the qualitative beliefs and experiences of participants must be examined.

In addition to the above areas of overlap, notable components of CFC services did not appear in the academic literature despite their clear benefits for service users. One such component was the restorative environment of Daisy Lodge and Narnia, which has been repeatedly stressed by service users. The facility offers top quality accommodation, catering, and amenities, whilst also remaining close to nature, overlooking the Morne Mountains. Despite the high levels of satisfaction reported by service users, none of the academic literature made reference to this characteristic. This suggests that such an environment may be unique to CFC and therefore warrants evaluation and investigation. The advocacy role played by ward and Cancer Support Specialists was also highly novel. While the focus of interventions in the academic literature appeared to be the development of advocacy skills among adolescents and young adults with cancer, CFC recognises that during hospitalisation and transition periods CAYA's may simply need someone to represent and speak on their behalf.

7.1.4 Challenges of Mapping

Mapping the current available literature to the work of CFC posed several challenges. As noted in the systematic review, primary studies were sometimes inconsistent in detailing their interventions and weighting the added value of intervention components in terms of affecting change. Furthermore, while components of the services provided by CFC clearly overlapped with the literature, the reach and scale of the work done by CFC often stretched beyond those of other identified interventions. Taking the residential work at Narnia as an example, this service appears most similar to the therapeutic camps identified in both the Moola and colleagues (2013) and Martiniuk and colleagues (2014) reviews. However, in contrast to many of the examined primary studies in these reviews, the Narnia residential work contains strong therapeutic components in all activities. Camp activities in the literature were often described as archery, rope courses, rowing, and horse-riding. In contrast to this, activities carried out in Narnia are constructed around pre-defined therapeutic goals (e.g. communication skills, resilience). Having been designed and run by trained social workers and counsellors, many of the activities facilitated peer-support and informal discussion elements which may aid in the development of coping strategies (Sansom-Daly et al., 2012). Creative workshops for example may involve learning how to share or communicate difficult or emotional experiences with other young people. While such an approach includes a number of the components deemed valuable within the included reviews, the sheer volume of therapeutic and supportive elements which

together form the intervention make it difficult to map on to existing literature.

A further challenge related to services addressing needs which were not identified in the literature. This was the case in both the ward and community support services, that provide one-to-one care and advocacy for children in hospital and at home. Again, the scope of these services are extensive. A four-week ward support service, for example, may include activities aimed at reducing boredom and isolation, exploring the emotional impact of hospitalisation, supporting the recognition and expression of emotions and feelings, and building resilience and self-esteem. Alongside these components, the CFC Ward Specialist may also act as advocates for the child within the wider multidisciplinary hospital team, ensuring that the informational, support, and medical needs of the child are understood and addressed. No interventions were identified in the literature which targeted CAYAs on the ward in this way. Further to this, while Zebrack and colleagues (2006) sought to foster advocacy skills in participants, no interventions provided a service which actively advocated on behalf of the individual needs of CAYAs with cancer. Therefore, the ward and community based support provided by CFC can be considered relatively unique and warrants robust evaluation.

Finally, though a number of reviews were identified in the literature, intervention research in this area remains in its early stages. As described by Meyler and colleagues (2010) studies often appeared as once off attempts to address gaps in the literature, meaning there is a marked lack of replication studies. Interventions were highly disparate, with small sample sizes, and reviewers often struggled to produce meaningful comparisons between approaches. Further to this, the recognised disconnect between what is clinically available and empirically validated limits the scope of comparative exercises and mapping efforts. At present, significant gaps in the research base exist, particularly in relation to what components of interventions are most impactful on outcomes. Though the services of CFC appear to address many of the needs highlighted in the literature, comprehensive evidence based evaluation of these services is not possible based upon the mapping process alone.

7.1.5 Areas for Development

In line with these challenges, a number of considerations for development are proposed. Consistent across the CFC services is the agency and autonomy afforded to their service users. While the examined academic literature repeatedly advocated for such an approach, this can also blur the scope of a service, creating challenges when both defining and categorising individual

interventions. This was exemplified in the 1:1 community support for a child with cancer. While the primary goal of this service is to develop a six session therapeutic programme for the child, interactions often extend beyond the 6 sessions and include support for parents and the broader family unit. While this service is highly valued among clients, it is important to consider the resource costs and burdens placed on Cancer Support Specialist services. Evident during the current mapping process was the need to better define and categorise the components, proposed outcomes and indeed the limits of these services. Achieving a balance between the needs of the client and the resources of the service is necessary not only to prevent burnout among staff, but to allow the proliferation and duplication of the service to greater numbers of young people. Economic evaluation techniques may help to disentangle the intrinsic short, medium and longer term personal and health service-related value provided by these programmes and could form part of the future research and evaluation efforts considered.

As noted previously, the scope of many services provided by CFC is broad. Within the community support service described above, specialists may engage in psycho-education, emotional and social skills training, advocacy and self-esteem development, as well as providing a space for individuals to explore their feelings, emotions, and understanding of this major life event. Similarly, within the Family Short Break programme, the scale of this service encompasses a multitude of components, from respite care, to massage and aromatherapy, to creative group work, facilitated by trained specialists. Capturing such services in a way that accurately conveys their reach is highly challenging. In the academic literature these are referred to as *complex interventions*. Furthermore, standardisation of such person-centred support programmes is not always possible, or preferable, given the multifarious needs presented by families and individuals. The current mapping process employed data extraction forms to summarise services. While these proved helpful, there is room to better adapt these tools for broader use by CFC. Appendix 5 proposes a 12 item extraction tool for use both when designing new services and summarising existing services.

Key to establishing evidence based practice within CFC services is recognising the potential areas of impact (needs), ensuring those areas are measured (outcomes), and ensuring that the correct tools are being used to do so (measurement tools). Ideally, services should strive to combine both qualitative (interviews, open ended questionnaires) and quantitative (psychometrics, Likert scales) approaches to fully encapsulate the experiences

of participants. Evident during the mapping process was the widespread recognition of the positive impact of CFC services on young people and their families. Quantifying and measuring this impact is the key next stage in the research process.

In line with the need for quantifying the impact of CFC, there is a clear need to more broadly evaluate the resource cost and scope for development within services. One potential method of approaching this is logic modelling, described as a graphical representation of the relationship between resources, activities, and results as they relate to a specific programme (Hayes et al., 2011). Designed using a series of “if then” relationships, logic modelling seeks to link both short and long term outcomes with “program activities/processes and the theoretical assumptions/principals of the program” (Pg.3, Kellogg, 2004). In this way, logic models may serve as a visual way of communicating distinct CFC services. Further to this, for those involved in delivering the service, logic modelling can also be helpful in thinking about how and why the service is impactful for participants. A sample logic model can be found in Appendix 6.

8. Key Findings, Recommendations and Future Directions

Evident from the current work is the highly valued and tangible impact CFC is having on CAYAs with cancer and their families. The services they provide show both a clear overlap with the academic literature base and a high degree of potential for contributing towards future research in the field. The following represent the key findings from the mapping process;

8.1 Key Findings

Box 7 Key Findings from Review and Mapping

7

- ✓ Services provided by CFC, particularly those within Daisy Lodge and Narnia, are addressing key areas of need routinely identified in the academic literature.
- ✓ The inclusion of family members in respite care services aligns closely with the academic evidence base and the continued focus on communication and coping skills as a means of improving family functioning is recommended.
- ✓ In line with the literature base, services should continue to utilise peer-support approaches when working with CAYA's, placing emphasis on fostering opportunities for informal knowledge and skill sharing.
- ✓ The current practice of affording service users a high degree of autonomy and control over their respite care is also supported by the current academic evidence, and may improve both engagement with services and positive outcomes for service users.
- ✓ Characteristic of the Daisy Lodge and Narnia services, such as the restorative environment, have not yet been investigated in the academic literature and should be further evaluated.
- ✓ No interventions in the academic literature matched the 1:1 Ward Support or 1:1 Community Support services.
- ✓ Both services appear highly novel and may potentially serve as blueprints for future interventions internationally.

Alongside these findings, a number of areas for further development emerged from the mapping process. The following box details recommendations and next steps for CFC and their services.

8.2 Recommendations

Box 8 Key Recommendations from Review and Mapping

8

- ✓ There is need for clear, common language around the definition and scope of individual services. Complex, multicomponent services such as 1:1 Community Support requires further refining and standardisation.
- ✓ Each service should have a commonly agreed service "pamphlet", including;
 - Reviews of psychosocial and supportive interventions for CAYAs with a cancer diagnosis
 - Areas of need addressed
 - Therapeutic characteristics of the service
 - Outcome goals of the service
- ✓ Working groups composed of staff and service users should contribute to the standardisation of service descriptions and the identification of target outcomes of treatment (e.g. self-confidence, family communication, knowledge around illness).
- ✓ Economic evaluation of current services is needed alongside consideration of the resource costs involved in individual service components.
- ✓ Combined quantitative (questionnaire/ psychometric tools) and qualitative (interview/ open ended survey) methods are needed for service evaluation across all services.
- ✓ There is need for a large scale controlled study examining the impact of CFC services on CAYA's with cancer and their families.

8.3 Concluding comments

We have thoroughly examined the literature that examines the effectiveness of support services for families, where a child experiences a diagnosis of cancer. We have also mapped the evidence to the services provided by CFC that best match this remit. Although the research is improving and becoming more sophisticated, there is still a lot to learn and discover.

The services at CFC are potential blueprints for effective evidence-based interventions in the area. There is scope for significant future research to confirm the impact and effectiveness of CFC services. This research would help to both identify and test the different components of the services delivered, in order to support and develop those components and combination of components that provide the most benefit for families. These key answers are needed to progress knowledge within the field and CFC are very well placed to support that process of knowledge generation.

Fostering an effective research culture within an organisation can be challenging and rewarding. The support for and the success of the current collaboration between CFC and Queen's University Belfast indicates that CFC is an organisation that is ready to embrace the future opportunities that an evidence-based culture can bring, particularly in terms of national and international impact. Ongoing collaborative efforts will continue to foster a drive towards measuring the impact of services, and the need to employ common language for communicating the work to clients, funders and policy makers on the national and international stage. Further rigorous independent evaluations and more advanced experimental research methods would be ideal to help to showcase the pioneering work that is underway. We look forward to taking these findings forward in future collaborations.

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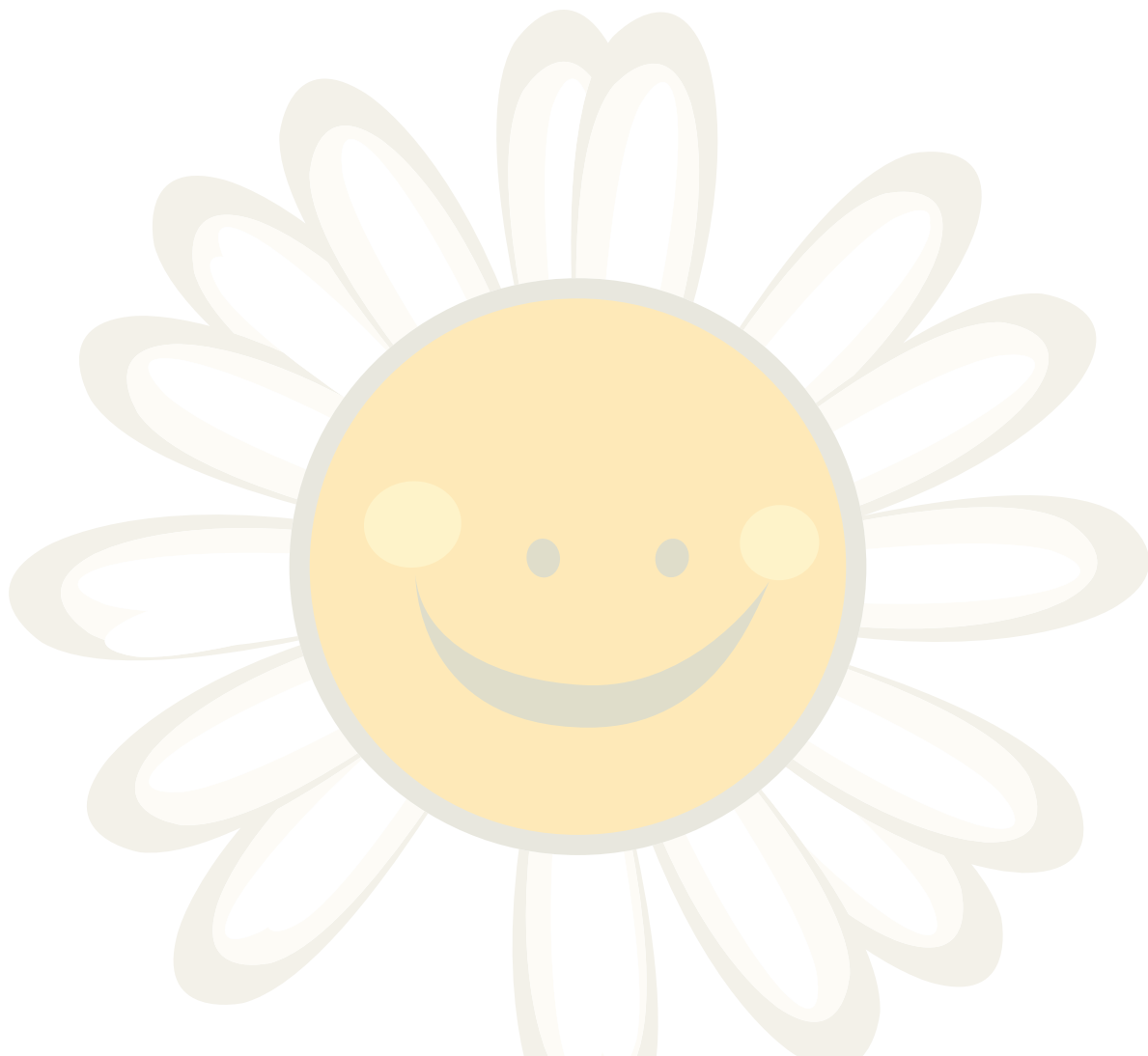
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Appendices



Appendix 1.1 Most prominent camping interventions across reviews

Reference	Design and Sample	Intervention overview	Results	Intervention Components
Barr et al., 2010 Canada	Historical Cohort Analysis 162 families of a child with cancer 76 camp attendees, 86 non-attendees	2-14 day <i>Camp Trillium</i> activities included swimming, archery, fishing, sailing, arts and crafts, and camping.	Parents reported better family functioning, social support, parenting and coping skills. Children had better HRQOL	Opportunities for relationship development Provision of; Emotional support (listening, empathy, encouragement, love and trust) Instrumental support (direct help with respect to time or materials) Informational and appraisal support (self-evaluation, comparison and affirmation that one's interpretations are appropriate)
Bluebond-Langer et al., 1991 USA	Participant observation and qualitative interviews 50 children aged 7-16 years.	1 week <i>Camp Can-Do</i> including swimming, archery, horseback riding, canoeing, group games, social dancing, model building	Children reported high satisfaction, formation of lasting relationships, improved knowledge around cancer and its treatment.	Peer-support Participants perceived empathy, understanding, and acceptance by other participants Informal knowledge sharing
Kiernan et al., 2005 Ireland	Qualitative 240 7-16 year olds with chronic illness	10 day <i>Barretstown Gang Camp</i> including arts and crafts, camping, horse-riding, and ropes courses	Development of social, psychological, and practical skills. Positive social experiences Meeting other children with similar illnesses.	Promotion of psychological and emotional well-being Encouragement of positive peer group interaction Practical skill development
Török et al., 2006 Hungary	Repeated measures 97 participants with cancer or diabetes	8-day <i>Camp Courage</i>	Positive changes observed for self-esteem and self-efficacy.	Councillors specifically trained in techniques for recognition and reinforcement of positive behaviours.
Wu et al., 2010 USA	Cross-sectional 89 children with cancer aged 5-18 years and their families	1-week <i>Camp Okizu</i> including swimming, fishing, archery, arts and crafts, rope course	Parents reported improved peer support for children, respite for themselves and children, improvements in child's behaviour and level of independence. Children reported high satisfaction, recreation opportunities, peer support, and respite	Both parent and child respite Supportive and safe environment Peer support Recreation opportunities

Appendix 1.2 Most prominent educational interventions across reviews

Reference	Design and Sample	Intervention overview	Results	Intervention Components
Canada et al., 2007 USA	Cross-over RCT 24 childhood cancer survivors, mean age 21 years	Enhancing psychosexual development through individual education session, behavioural homework, and booster phone calls.	Significant improvement in cancer related sexual knowledge, self-confidence and body perception. Reduced sexual concern, dissatisfaction with body parts, decrease and emotional distress.	Delivered by doctoral level psychologist Combined education and counselling Follow-up sessions and phone-calls
Hinds et al., 2000 USA	Randomised longitudinal two-group design 78 patients with cancer aged 12-21 years	Facilitating self-coping skills through information provision and rehearsal of strategies.	No significant improvement in intervention group relative to controls	No details on clinical qualifications of facilitators.
Jones et al., 2010 USA	RCT 65 participants with cancer aged 12-18 years	Educating adolescents about cancer through an interactive multimedia CD-ROM covering cancer, research, treatment, side effects, long-term effects, and resources	Improved locus of control No other significant findings	Use of media and technology Novel and innovative approach
Kato et al., 2008 USA	RCT 375 participants with cancer aged 13-29 years	Video game aimed at improving treatment adherence and health-related behaviours. Players must use positive self-care behaviours to win.	Improved self-efficacy Improved treatment adherence	Use of media and technology Novel and innovative approach
Wu et al., 2013 Taiwan	RCT 61 participants with cancer, mean age 13.2	Psychoeducational intervention aimed at identifying stressors related to side-effects of illness, self-help methods to generate coping skills, group sharing of positive coping experiences.	No significant differences observed between groups. Acceptability of intervention was confirmed, particularly opportunities to share experiences with others.	Inclusion of skill development components Use of peer-support approach

Appendix 1.3 Most prominent peer-support interventions across reviews

Reference	Design and Sample	Intervention overview	Results	Intervention Components
Baider & Kaplan De-Noir 1989 Israel	Before and after study 8 participants with cancer aged 15-25 years	Weekly group therapy sessions lasting 1.5 hours. Themes were dynamic and based upon participant needs	No significant effect of group therapy on psychological symptoms of participants. Psychological distress increased for participants in active-treatment versus off-treatment	Flexible participant led approach Shared experience between participants fostered familiarity and group bonding
Heiney et al., 1989 USA	Non-randomised control study 14 participants with cancer aged 14-19 years	6 weekly 1-hour structured group therapy sessions covering topics of diagnosis, treatment, school and peer relations, parents and the future	No differences in anxiety, depression, self-esteem, or locus of control. Group helped in coping with stressors, isolation from peers, and over-protective parents	Peer-support provided catharsis and commonality Groups were run by trained therapists
Love et al., 2012 USA	Qualitative 350 randomly sampled posts from an online AYA cancer forum	Online discussion forum open to any young adult affected by cancer.	Themes included; Exchanging support Coping Describing Experiences Enacting Identity Communicating membership	Technology based online forum Non-structured approach Peer interaction and support Development of trust Opportunities for catharsis Shared experiences
Schwartz et al., 1999 USA	Pre-post intervention and case-control 23 participants with cancer aged 18-29 years	3-Day <i>Moving On</i> programme, providing facilitated group discussions, formal presentations, and group activities. Led by two social workers.	No significant group differences were observed in physical or mental health functioning or psychological wellbeing. Quality of life improved following intervention, though change did not last	Combined peer-support and educational components Opportunities for shared experience
Zebrack et al., 2006	Qualitative 35 AYAs <39 years	4-day <i>Camp Māk-a-Dream</i> involved combined advocacy and peer discussion workshops around self-care and survivor needs, mentoring and communication, and policy involvement.	Most positive aspects of experience included; Opportunities to meet other AYAs Development of lasting friendships Increased cancer knowledge Improved self-advocacy skills	Combined elements of education provision, skill development, peer-support, and therapeutic camp retreat.

Appendix 1.4 Most prominent skills based interventions across reviews

Reference	Design and Sample	Intervention overview	Results	Intervention Components
Kazak et al., 2004 USA	RCT 76 families of children with cancer aged 10-19 years	1-day <i>Surviving Cancer Competently Intervention</i> Program combined CBT and family therapy delivered by a multidisciplinary team of psychologists, social workers, and nurses over four sessions.	Intervention group showed reduction in PTSS symptoms.	Facilitated by trained clinicians Inclusive of both children with cancer and family members. Combines aspects of education, skill development, and peer-support.
Varni et al., 1993 USA	RCT 77 participants with cancer aged 5-13 years	3 60-minute social skills trainings, covering; social cognitive problem-solving, assertiveness training, and handling teasing and name-calling, were provided alongside regular school re-integration services. Detailed handouts were also provided to promote generalisation of skills.	Improvements in perceived teacher, and peer social support within intervention group. No lasting differences found between intervention group and controls receiving standard school re-integration services.	Skills training was complimented by homework to promote generalisation of learned behaviours. Opportunities were provided for behaviour modelling.

Appendix 2. References for Primary Research Studies

Review Article	Primary Study
Bradford & Chan, 2017	Blaauwbroek R, Bouma MJ, Tuinier W, Groenier KH, de Greef MHG, Meyboomde Jong B, et al. The effect of exercise counselling with feedback from a pedometer on fatigue in adult survivors of childhood cancer: a pilot study. <i>Support Care Cancer</i> 2009;17 (8):1041–8. http://dx.doi.org/10.1007/s00520-008-0533-y .
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Review Article	Primary Study
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Seitz et al., 2009	
Walker et al., 2016	

Appendix 3. Sample of measures used in primary intervention studies.

Outcome	Measure	Availability
Anxiety/Stress	State-Trait Anxiety Inventory for Children	Paid
	Perceived Stress Scale	Free
	The Revised Children's Manifest Anxiety Scale	Paid
	Hopefulness Scale for Adolescents (HAS)	Free
	The Hopelessness Scale for Children (HPLS)	Free
Coping	Coping Health Inventory for parents	Free
	Adolescent Coping Scale (ACS)	Paid
	Kansas Coping Inventory for Children	Free
	Coping Scale for Children and Youth	Free
	Ways of Coping Checklist	Free
	Katz Adjustment Scale (KAS-R1)	Free
Self-efficacy/concept	Primary Self-Concept Inventory	Paid
	Self-Perception Profile for Children	Paid
	Self-Perception Profile for Adolescents (SPPA)	Free
	General Perceived Self-Efficacy Scale	Free
	Rosenberg Self-esteem Scale	Free
Family adaption/functioning	Family Adaptation Scale	Free
	McMaster Family Assessment Device (FAD)	Free
	Family Environment Scale (FES)	Paid
	Family Adaptability and Cohesion Evaluation Scales	Paid
	Parenting Stress Index: Short Form (PSI/SF)	Paid
	Sibling Perception Questionnaire	Free
	Impact on Family Scale (IOF)	Free
Social support/loneliness	Children's Loneliness and Social Satisfaction Questionnaire (CLSSQ),	Free
	Social Support Scale for Children (SSSC)	Free
	Multidimensional Scale of Perceived Social Support	Free
	Duke Social Support Index (DSSI)	Free
	Social Skills Ratings System (SSRS)	Paid
	UCLA Loneliness Scale	free
	Berkman-Syme Social Network Index	Free
Knowledge/Attitude towards illness	Children's Attitude Toward Illness Scale (CATIS)	Free
	The Perceived Illness Experience Scale – revised	Free
	Brief Symptom Inventory (BSI)	Paid

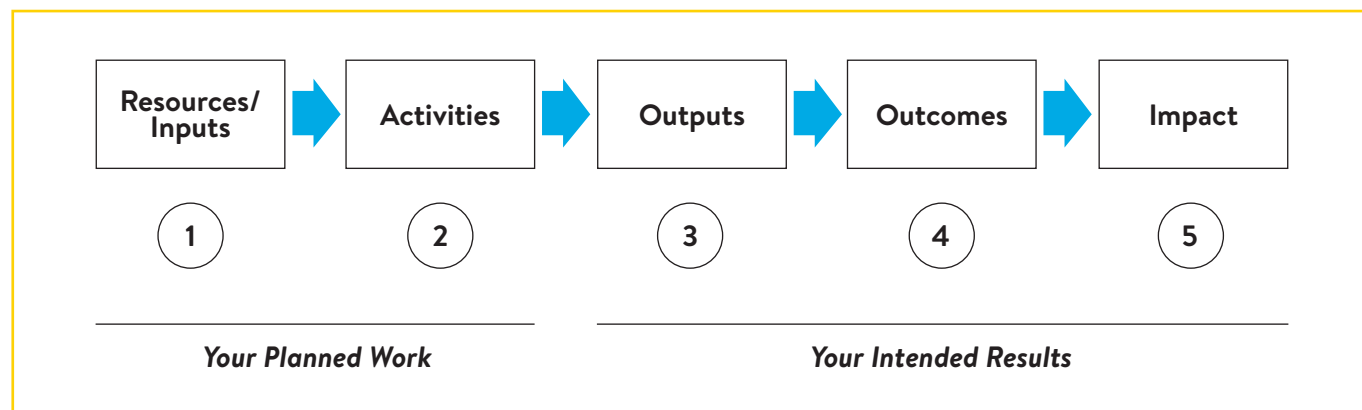
Appendix 4. Sample of international organisations providing interventions for CAYAs with cancer

	Intervention	Contact details
Barretstown Fun Camp	Camp for children with chronic illness (IE)	info@barretstown.org
Over The Wall	Camp for children with chronic illness (UK)	info@otw.org.uk
Camp Mak-A-Dream	Camp for children, teens, and young adults with cancer (USA)	info@campdreammich.org.
CLIC Sargent	Respite and financial support (UK)	supporter.services@clicsargent.org.uk
Kensington Foundation	Respite and financial support (UK)	foundation@kensingtonhealth.org

Appendix 5. Proposed Data Extraction tool for evaluation and development of CFC services

Service Title	
Aim/ objectives of service	
Brief summary of service (e.g. length of service, activities, setting, 1:1, family groups, peer groups)	
Participant needs being addressed	
Characteristics of Participants (Typical number of participants, age range, stage of treatment)	
Discipline of facilitators (e.g. nurse, counsellor, social worker)	
Resource costs (e.g. number of staff members, travel time, materials)	
Outcome measurement tools (e.g. participant feedback, survey questionnaire, psychometrics)	
Outcomes measured (e.g. family togetherness, resilience, reduced stress, improved illness knowledge)	
Summary of primary results	
Limitations/challenges	
Recommendations for service design/provision	

Appendix 6. Sample Logic Model



A logic model is a diagram showing how an intervention produces its outcomes and impacts. It represents a hypothesis or ‘theory of change’ about how an intervention works. **Logic models** help us to better understand the impact of complex interventions such as those delivered by Cancer Fund For Children, and the mechanisms which make them work. A strong **logic model** helps with evaluation design, data collection, and analysis, and is a useful framework for interpreting evaluation results. Creating logic models that represent the supportive interventions provided by Cancer Fund for Children would enhance the value of evaluation data for service development.